

A POETIC NARRATIVE INQUIRY INTO THE LIVES OF PEOPLE WITH LYME DISEASE

A DISSERTATION

SUBMITTED TO THE GRADUATE SCHOOL

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE

DOCTOR OF EDUCATION

IN ADULT, HIGHER, AND COMMUNITY EDUCATION

BY

AMY M. BAIZE-WARD

DISSERTATION ADVISOR: DR. MICHELLE GLOWACKI-DUDKA

BALL STATE UNIVERSITY

MUNCIE, INDIANA

DECEMBER 2018

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BALL STATE UNIVERSITY

MUNCIE, IN

DECEMBER 2018

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## **DEDICATION**

I have struggled for many years realizing that I could no longer share my story through song. I found my voice again, only this time through the power of the written word. That would never have happened without walking through my own journey with Lyme disease and believing in the path that God has for my life. From a Celine Dion song, Because You Love Me, I honor some very special people to whom this piece of work is dedicated.

### **Steve and Ginny Baize, my parents.**

For all the times you stood by me, for all the truth that you made me see, for all the joy you brought to my life, for all the wrong that you made right. For every dream you made come true, for all the love I found in you, I'll be forever thankful. You're the ones who held me up, never let me fall, you're the ones who saw me through it all. (Warren, 1996, Stanza 1)

I am grateful that you were always there to listen, to read my work, and for the many hours you researched with me. I am glad we took this journey together.

### **Ted Ward, my husband.**

You gave me wings and made me fly. You touched my hand; I could touch the sky. I lost my faith; you gave it back to me. You said no star was out of reach. You stood by me, and I stood tall. I have your love; I have it all. (Warren, 1996, Stanza 2)

Thank you for loving me through this journey and for always having the answers on your forehead! Our talks and debates always provided the insight needed to continue.

**Bryant and Nathaniel Wagner, my sons.**

You were always there for me, the tender wind that carried me. A light in the dark shining your love into my life. You've been my inspiration, through the lies you were the truth. My world is a better place because of you. (Warren, 1996, Stanza 3)

Thank you for the hugs, the phone calls, the "Dr. Moms", and the support and understanding when I had to cut a visit short or turn down an invitation. You boys have always been my why and I hope I proved to you that nothing is impossible with God and family leading the way. Sara Wagner, my compassionate daughter-in-law, thank you also for being a rock for our family when I was not available.

**Eric Baize, my brother.**

You were my strength when I was weak. You were my voice when I couldn't speak. You were my eyes when I couldn't see. You saw the best there was in me. (Warren, 1996, Chorus)

God gave me a pillar in you. Thanks for always holding me up and pushing me forward.

**Lyme friends.**

Those that knowingly suffer with Lyme disease and those that are struggling to get a solid diagnosis, my hope is that this and future studies help educate or make much needed changes within the Lyme community. Thank you for your willingness to share your stories for this study and for your friendships.

## ACKNOWLEDGMENTS

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**Dr. Chang:** Thank you for always being there to challenge my thought process and to ask tough questions about my future and my contributions to research. You have always provided me with opportunities for critical thought and reflection.

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Much love to you all!!

## **ABSTRACT**

**DISSERTATION:** A Poetic Narrative Inquiry Into the Lives of People With Lyme Disease

**STUDENT:** Amy M. Baize-Ward

**DEGREE:** Doctor of Education in Adult, Higher, and Community Education

**COGNATE:** Community College Leadership

**COLLEGE:** Teachers College

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Stories of people becoming critically ill with Lyme disease are finally starting to emerge within communities and social arenas. For many, there is a sigh of relief, and for others, there is a sense of confusion and concern. Lyme disease has affected people for many years. Most of the literature focuses on medical treatments, issues with medical coverage, and the lack of medical acknowledgement. Few research studies exist that include personal stories and experiences that people with Lyme disease face daily. This study was designed to learn, understand, and describe how people with Lyme navigate the disease.

People with Lyme disease experience transformation within their everyday lives, a becoming of a different person. Their stories, as experienced through narrative inquiry, allow new knowledge to be gleaned through their journeys. Additionally, learning from one another within a community of support helps to educate and inspire everyone associated with the disease.

The realities of living with Lyme disease are hard to understand and resolve. Not unlike other diseases, it is imperative to learn about the effects of this disease. Recognizing coping strategies and understanding medical, nutritional, and other Lyme-related information is valuable. This poetic narrative inquiry provides an opportunity for those who suffer with Lyme



disease to share their experiences. The stories told through poetry will provide new insights and a more robust understanding of what people with Lyme disease face daily.

## TABLE OF CONTENTS

DEDICATION .....	IV
ACKNOWLEDGMENTS .....	VI
ABSTRACT.....	VIII
TABLE OF CONTENTS.....	X
LIST OF TABLES AND FIGURES.....	15
CHAPTER ONE .....	1
INTRODUCTION .....	1
HISTORY OF LYME .....	2
PROBLEM STATEMENT .....	5
CONCEPTUAL FRAMEWORK .....	6
NARRATIVE INQUIRY DESIGN .....	8
PURPOSE OF THE STUDY .....	9
POSITIONALITY STATEMENT .....	10
RESEARCH QUESTION .....	11
SIGNIFICANCE OF THE STUDY .....	11
ASSUMPTIONS .....	12
DEFINITIONS .....	12
CHAPTER SUMMARY .....	13
CHAPTER TWO LITERATURE REVIEW .....	14
INTRODUCTION .....	14

COMMUNITY EDUCATION .....	14
<i>Informal Learning</i> .....	16
<i>Resources Shared</i> .....	17
<i>Social and Ethical Responsibilities of Community Educators</i> .....	18
SIX DIMENSIONS OF WELLNESS .....	19
<i>Occupational Wellness</i> .....	21
<i>Physical Wellness</i> .....	22
<i>Social Wellness</i> .....	22
<i>Intellectual Wellness</i> .....	23
<i>Spiritual Wellness</i> .....	23
<i>Emotional Wellness</i> .....	24
<i>Meaning of Wellness</i> .....	25
NARRATIVE MEDICINE.....	25
<i>Chronic Disease</i> .....	26
LYME DISEASE.....	27
POETIC STORYTELLING .....	43
CHAPTER SUMMARY .....	32
CHAPTER THREE METHODS .....	33
INTRODUCTION .....	33
QUALITATIVE RESEARCH.....	33
RESEARCH QUESTION .....	35
NARRATIVE RESEARCH.....	35
RESEARCH DESIGN .....	39

<i>Narrative Inquiry</i> .....	39
<i>Narrative Knowing</i> .....	40
<i>Trust and Openness</i> .....	42
<i>Ethical and Critical Engagement</i> .....	43
<i>Storyteller, Both Voices Heard</i> .....	43
<i>Reflexive Engagement</i> .....	45
<i>Tolerance of Ambiguity</i> .....	46
RESEARCHER’S STATEMENT .....	48
ASSUMPTIONS .....	48
SELECTION AND COLLECTION .....	48
DATA COLLECTION .....	50
<i>Sampling</i> .....	50
<i>Semi-Structured Interviews</i> .....	51
<i>Transcription</i> .....	54
<i>Confidentiality of Data</i> .....	55
<i>Trustworthiness and Consistency</i> .....	55
DATA ANALYSIS .....	55
TRUSTWORTHINESS.....	58
CHAPTER SUMMARY .....	59
CHAPTER 4 – FINDINGS.....	61
INTRODUCTION .....	61
THE GROUP .....	63
PARTICIPANTS .....	64

PARTICIPANT DEMOGRAPHICS AND NOTES .....	51
SUFFERING FOR WISDOM, OUT OF BALANCE.....	66
POETRY DERIVED FROM INTERVIEWS .....	67
<i>Ellen</i> .....	67
<i>Jamie</i> .....	70
<i>Cassey</i> .....	72
<i>Ericka</i> .....	74
<i>Sindy</i> .....	76
<i>Leah</i> .....	78
<i>Kim</i> .....	80
<i>Peter</i> .....	82
THOUGHTS ABOUT INTERVIEWS .....	84
MEDICAL ASPECT .....	85
<i>Dr. Jemsek</i> .....	86
<i>Dr. Len</i> .....	88
CHAPTER SUMMARY .....	89
CHAPTER 5 – DISCUSSION .....	91
INTRODUCTION .....	91
DISCUSSION OF THE FINDINGS .....	91
<i>Recognizing the Six Dimensions of Wellness in Lyme Patients</i> .....	92
<i>Community Education and Lyme Disease Support Groups</i> .....	95
RECOMMENDATIONS FOR PATIENTS AND FAMILY MEMBERS .....	99
RECOMMENDATIONS FOR MEDICAL PROVIDERS .....	100

RECOMMENDATIONS FOR POLICY MAKERS .....	101
RECOMMENDATIONS FOR RESEARCHERS .....	102
RESEARCHER REFLECTIONS .....	104
RESEARCH CONCLUSION AND IMPLICATIONS.....	105
CHAPTER SUMMARY .....	106
REFERENCES .....	108
APPENDIX A IRB APPROVAL .....	121
APPENDIX B INFORMED CONSENT – DISSERTATION .....	122
SURVEY INFORMED CONSENT FORM.....	122
APPENDIX C PARTICIPANT RECRUITMENT.....	125
APPENDIX D SEMI-STRUCTURED INTERVIEW QUESTIONS .....	126

## **LIST OF TABLES AND FIGURES**

<b>TABLE 1. PARTICIPANT DEMOGRAPHICS.....</b>	<b>51</b>
<b>FIGURE 1. WHAT IS LYME.....</b>	<b>13</b>
<b>FIGURE 2. THE SIX DIMENSIONS OF WELLNESS .....</b>	<b>28</b>
<b>FIGURE 3. WHAT CAN LYME DISEASE FEEL LIKE .....</b>	<b>37</b>
<b>FIGURE 4. LIBRARY STATUE.....</b>	<b>57</b>

## CHAPTER ONE

*Lyme is like living in some sort of 'torture box' 24 hours a day 7 days a week. There is no escape. Nobody in your life understands the suffering. It's surreal. It's inhumane.*

*—Jen, Lyme Survivor (Sophantastic, 2017)*

### Introduction

One day you are feeling great, the next your world is upside down, maybe quite literally with vertigo. Maybe you woke up this morning and for some unexplained reason you can no longer walk. Maybe you have been experiencing signs and symptoms of the flu with night sweats, a non-stop running nose, and chills that can only be attributed to a fever. Symptoms that will not go away, leaving one to wonder what is going on.

Heading to the doctor for what you think is a routine appointment to obtain antibiotics in order to treat these nasty little “normal” cold symptoms. Two weeks later having symptoms getting worse, medications not working, doctors passing you around from specialist to specialist because nobody can determine the medical issue. Then, after months, and most generally years, of bouncing from doctor to doctor, still with no answers, Horowitz (2013) stated that patients start getting tired of hearing that their sickness is all in their head and a diagnosis is still unknown. What is this illness and why are people sick with multiple symptoms that mirror so many critical illnesses, the great imitator (Fallon, 2004) has taken control of their life.

Lyme disease changes the lives of people in many ways. The cases are growing in number, not just locally but around the world, and there is very little support from the medical field. McFadzean (2012) stated that in year 2000 there were approximately 17,730 confirmed and reported cases of Lyme disease, and by 2009 the number had almost doubled to 29,959. Today, when reading reports from the Center for Disease Control (CDC, 2015) the approximate



number of new cases of Lyme disease is growing at a rate of over 300,000 confirmed cases per year.

The statistics prompt questions of why are people with Lyme disease being ignored, and where do we find the answers to obtain help and support? There are many different views regarding what Lyme disease is, acute or chronic. There are more people becoming deathly ill and dying from this disease, from children to young adults to the elderly. Yet, where are the policy makers and medical professionals and why are they not willing to take a stand to help?

While this is a small study, I seek to better understand the meaning of the experiences that my participants live daily, and hope those who have the power to take this research further will do so. I want to share the experiences and journeys through poetry, so that patients' voices are heard and that their struggles matter. This approach affords us the opportunity to interpret meaning and provide collaborative action to empower transformation of policies and practices over time.

### **History of Lyme**

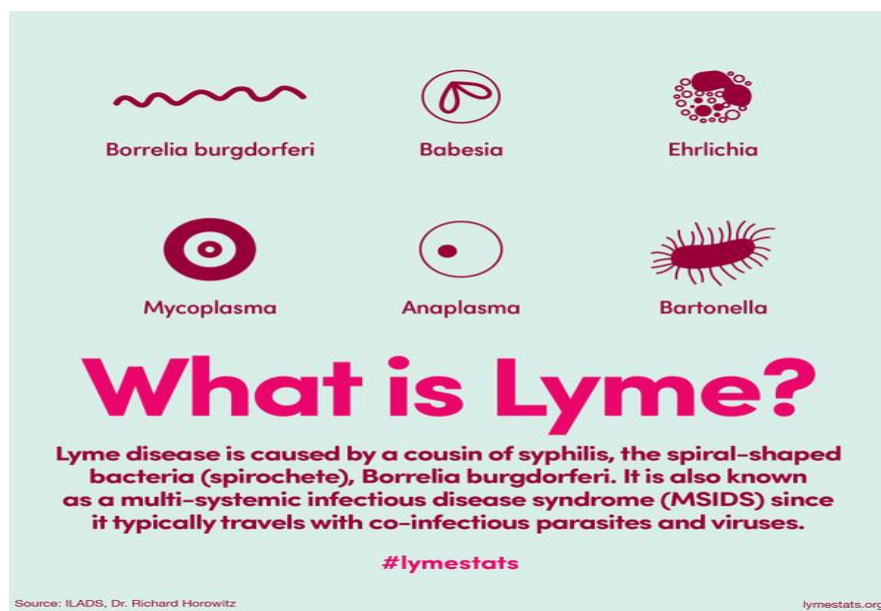
The story of Lyme begins in controversy and continues today with different types of controversy, but controversy just the same. McFadzean (2012) stated that Lyme disease dates as far back as 1764, with Reverend John Walker discovering the disease while visiting Scotland. There is not much else said about Lyme disease until 1894 when it was then discovered in Germany and in the United States within Cape Code, Maine.

Conversations regarding Lyme do not start again until the 1900s. This is when children, according to Yardley (2014), started becoming ill with rashes, fevers, swollen joints, and many more serious symptoms within Lyme, Connecticut from an illness then called Lyme arthritis. Cocks (2014) shared that Lyme disease was finally getting

attention within the medical field in the 1970s, and it quickly became one of the most controversial diseases in medical history. In 1975, what is known as “Lyme Wars” (Cocks, 2014) began to take place between the major-medical insurance providers, scientists, and physicians. Throughout these wars, patients suffered because treatments were delayed, cost of potential medicines to treat the disease rose, and “insurance companies cut off benefits to ‘Lymies’ ” (Cocks, 2014, p. 7). Unfortunately, these wars are still going on today.

Much of the literature states that Lyme disease, as we know it today, was actually discovered by Dr. Wilhelm Burgdorfer, a medical entomologist. Yardley (2014) stated that Wilhelm was born on June 27, 1925 and received his undergraduate and doctoral degrees from the University of Basel and the Swiss Tropical Institute in Basel, where he specialized in zoology, parasitology, and bacteriology. Because of his educational background and life’s work, in 1982, he identified the cause of the mysterious affliction which is known as Lyme disease today. Yardley (2014) shared that Dr. Burgdorfer moved to Hamilton in 1951 to pursue his “tick surgery”. This tick surgery was nothing more than the dissection of ticks to study disease(s) they spread.

In the early 1980s, Dr. Burgdorfer analyzed a deer tick, thought to cause Rocky Mountain spotted fever. Yardley (2014) shared that Dr. Burgdorfer found, while looking through the microscope, spirochetes which are corkscrew shaped disease causing bacteria.



**Figure 1:** Horowitz, R. (n.d.). *What is Lyme?* Retrieved from [doctorsbestimmediatecare.com](http://doctorsbestimmediatecare.com)

Understanding this bacteria causing parasite Dr. Burgdorfer was able shed much needed insight into the disease that over 300,000 people are diagnosed with and suffer from each year. Because of his discovery, the bacterium that causes Lyme disease has been named *Borrelia burgdorferi*. *Borrelia burgdorferi* in his honor, and in 1986, Dr. Burgdorfer retired after winning numerous awards for his discovery and contribution to this medical phenomenon (Yardley, 2014).

McFadzean (2012) provided additional history of Lyme disease, and he set the stage for this study, along with the stories that were gathered. Approximately 47 years ago a Lyme, Connecticut housewife named Polly Murray, her family, and neighbors all became ill with symptoms that did not make sense. Mervine (2014) wrote that after Polly was misdiagnosed, misunderstood, and dismissed by doctors, she was able to convince the public health authorities to investigate and the diagnosis received was called “Lyme arthritis” (p. 15).

In the mid-1970s many medical professionals on the East Coast of the United States were also faced with a disease they could not explain. During this time of unexplained illness, many children were becoming deathly ill. As the number of people starting to become critically ill increased, Dr. Wilhelm Burgdorfer did not accept the diagnosis that Polly Murray and others were receiving. By 1982, after intensive research, he found the organism that was causing the issues, a spirochete named *Borrelia burgdorferi* (Bb), which earned its name from his discovery (Horowitz, 2017). During an interview Wilhelm stated, “It was not an Aha moment. It was a “what the hell? What’s in that smear?” And then my work as a Swiss student came back. I said to myself, Willy, these are spirochetes!” (Mervin, 2014, p. 18).

### **Problem Statement**

Lyme disease is an illness that is growing at a rapid pace and those with the disease are not being heard. In 2016, Chaaya, Jaller-Char, and Ali stated, “Lyme disease is the most common tick-borne illness in the United States, with more than 25,000 cases confirmed in the country in 2014” (p. 373). The symptoms of Lyme disease are many, and receiving an accurate diagnosis takes time and, often, a lot of unnecessary medical visits with multiple specialists. This delayed diagnosis uses time, which many people do not have. Once bitten by a tick, or other insect that is a Lyme disease carrier, and if not treated quickly, the illness can lead to chronic and severe sickness.

Once people reach the chronic stage of Lyme, there are no over-the-counter or common prescriptions that can cure the infections caused by the disease. Maraspin, Ruzic-Sabljić, Lusa, and Strle (2015) shared that at the first visit many patients were treated with doxycycline for 15 days. This treatment may attack some of the issues, but many people have to rely on holistic medical approaches that do not utilize prescriptions and are not covered by insurance, just to

experience a small glimmer of relief. Wickens (2005) continued the conversation by sharing that vaccines come and go, and treatment regimens compete for efficacy and reliability, however there is still hope.

Within the medical field and the Center for Disease Control (CDC, 2015) the mention of chronic Lyme disease causes controversy associated with insurance and treatments. The controversy does not end there as it carries over to patients and the experts who are trying to determine exactly what chronic Lyme disease is, why only some patients get chronic manifestations, and how to treat the disease (Rowe, 2000). These continuous conversations and debates are a great concern to patients and medical professionals alike. With this knowledge, the goal for this research was to allow chronic Lyme disease patients voices to be heard through the sharing of their stories by way of poetry.

### **Conceptual Framework**

The purpose of this narrative inquiry was to understand Lyme disease as told by those that have the disease. Through a constructivist paradigm ontological lens on the inquiry of individual perspectives (Creswell, 2013), I acknowledge that multiple realities exist because of the unique experiences that Lyme patients face. The epistemology allowed the participants and I, as the researcher, to join together and co-construct knowledge to raise awareness through participants' stories within narrative inquiry. Through a theoretical perspective that allowed for symbolic interconnectedness to emerge, the values constructed allowed for poetic storytelling to express the experiences.

Hatch (2002) stated that through interviews, observations, and researcher journaling rich narratives emerge allowing readers to immerse themselves in the stories of the participants. According to Denzin and Lincoln (1994), terms like credibility, transferability, dependability,

and confirmability provide a foundational truth when stories are shared. Defining these terms showed their importance to the research. Credibility expressed that what was being shared is truth for the participant because it is their reality. Transferability allowed for the researcher and the participant to knowledge share through dialogue. Dependability of the information shared was seen through multiple stories stating the same or similar information. Finally, confirmability was realized through facts that are shared and understood through additional research. Narrative inquiry is a practice that is filled with bits and pieces of storied moments that allow reflection into a reality (Clandinin & Connelly, 2000).

Human beings have lived out and told stories about that living for as long as we could talk. And then we have talked about the stories we tell for almost as long. These lived and told stories and the talk about the stories are one of the ways that we fill our world with meaning and enlist one another's assistance in building lives and communities. What feels new is the emergence of narrative methodologies in the field of social science research. (Clandinin & Rosiek, 2007, p. 35).

This study is being designed as a narrative inquiry. Savin-Baden and Howell Major (2013) stated,

The central point is that people's lives are storied and researchers re-present them in storied ways . . . Narrative theory is a way of understanding the human experience, narrative as data, narrative as a specific method, and narrative as a research product. The process of telling the story as well as the product, the story itself, is important. (p. 227)

The intent was to interpret the meanings others have about the world (Creswell, 2013) while living and coping with Lyme disease. This responsibility of interpreting aimed to show alternative and adequate decision making (Baalen & Boon, 2015) through a creative expression of poetry.

Using an understanding of the subjective and inter-subjective interpretation of the social reality (Brglez, 2001) provided a transformative lens suggesting that the participants raise their consciousness and improve their lives (Creswell, 2013) through knowledge shared. This sparked learning with practical meaning that brings about a deep reflective change in the individual's perception of self and the world (Moyer & Sinclair, 2016). Using both lenses, we constructed knowledge that can better educate those around us of the experiences faced when living with Lyme disease.

### **Narrative Inquiry Design**

Denzin and Lincoln (2011) shared that the goal of narrative inquiry is to work collaboratively with research participants to share their everyday experiences. When researchers study narrative as experiences or journeys a construction of meaning is realized. Researchers use in-depth interviewing along with observation and journaling to construct meaning. The researcher, according to Denzin and Lincoln (2011), can utilize detailed transcripts and their personal experiences to creatively express the stories shared.

Telling a story of the lives that are being lived with Lyme disease lends itself to the style of narrative inquiry. Connelly and Clandinin (1990) shared that humans are storytelling people and the way in which human's experience the world is shared more educationally through the construction of stories. Utilizing narrative inquiry allows for rich descriptions of experiences to

be expressed in a variety of ways. Connelly and Clandinin (1990) expressed that narrative inquiry can be creatively used to clearly understand patients experiences and viewpoints.

Creswell (2013) shared that researchers collect stories from individuals to convey a message. The story that emerges tells of the individuals experiences and provides an identity that links the topic of the study to the participant through different points that are shared. According to Creswell (2013) the findings that will be reported out can be a poem, a play, or another dramatic rendering. For this study poems will be used to express the events of the narrative inquiry.

### **Purpose Of The Study**

Creswell (2013) stated that in qualitative research “the study reflects the history, culture, and personal experiences of the researcher” (p. 54). As a diagnosed chronic Lyme disease patient myself, I understand the struggles and the issues, and have my own thoughts related to healing and what keeps me going along this journey. Through this study, I began to understand how others are experiencing and living with this disease. While I have a bias toward this disease, I do not wish to voice most of my own story at this time, as my goal is to learn from others in different stages of this disease.

In order to help people understand the disease and the persistent, post-infection symptoms of this illness that have also been reported following other-infectious diseases (Aucott, Rebman, Crowder, & Krotte, 2012) more thoroughly, I sought information from others and see where the transformations occur. Through this study, I heard and understood their journeys and stories and, with this knowledge, could help educate others by sharing these experiences. Therefore, obtaining a better understanding of how those living with Lyme have faced their



journey is a critical component. This study and the information that follows is critical to changes needed within the Lyme community.

### **Positionality Statement**

In full disclosure I have a bias to this study, and while I share some of my story, my focus is to hear and share the experiences and journeys of others. The primary reason for this research is to allow for conversations to begin and to show that advocacy and research are needed regarding Lyme disease.

In 2006, I started having medical issues that could not be explained. They started as flu like symptoms and after several visits to the doctor's office it was decided that something more was going on, but there was no definitive answer. By 2012, with still no answers, I was visiting seventeen specialists and still receiving no relief. In 2013, I chose to not see any medical professionals, it was just too painful to hear that there was nothing wrong with me and that my symptoms were just in my head. Then in May of 2014, I woke and was unable to walk and had to visit a medical professional. It was decided that a Western Blot blood test would be performed. Two weeks later, I was officially diagnosed as CDC positive with Chronic Lyme disease and thirteen co-infections.

My journey has taken many twists and turns. I have struggled finding a physician that would treat me for Lyme. Those that I have found only provide holistic treatments which are all natural and are not covered by insurance. The reality is that I have good days and bad. The bad are debilitating and the good days are mediocre at best. I struggle with many symptoms and the most common are extreme fatigue, brain fog, memory loss, and major amounts of pain from tip to toe.

### **Research Question**

There are so many questions that could be asked for this study. I chose, however to keep the research focused on the following question:

- How do the participants narrate stories about their experience living with Lyme disease?

### **Significance Of The Study**

The significance of this study is two-fold. First, this narrative inquiry gathered stories related to the participants' journeys with Lyme disease and utilized words and quotes from interviews that served as a window into their lives and struggles. The intent was to interpret the meanings others have about the world (Creswell, 2013) of Lyme that they live with daily. This epistemological responsibility showed alternative and adequate decisions that patients and supporters have to make when facing the diagnosis, treatment, and pathways of healing Lyme disease (Baalén & Boon, 2015).

This study was intended to help people understand the disease and the persistent, post-infection symptoms of this illness that have also been reported following other-infectious diseases (Aucott et al., 2012). In this research, I sought information from others and see where they were seeking knowledge and to understand better where their lives were out of balance. My ultimate goal was to understand their journeys and stories to cultivate new knowledge and to help educate others by sharing these experiences. Therefore, obtaining a better understanding of how those living with Lyme experience healing and cope with this disease was critical to this study.

The second significant piece of this research was personal. I am a person that has been diagnosed with chronic Lyme disease, an invisible illness, and I struggle daily with people not

believing that I am ill. My outside looks normal, but the internal struggle with multiple symptoms that I have to overcome leaves me, at times, very alone and struggling to lead a normal life. I am very interested in how others experience this journey to provide myself with encouragement, hope, and support.

### **Assumptions**

My assumptions for this study are that most people are being misdiagnosed because medical professionals have very little knowledge about Lyme disease. From my personal experiences, I believe that there is no specific cure for Lyme disease and that the longer it goes untreated the more ill people become. Additionally, I believe that there are multiple ways to mask or ease symptoms. This disease, from my twelve years of experience behaves in manners that reminds one of other chronic illnesses. I know that Lyme disease is misdiagnosed, throws people's lives out of balance, can go into remission, can return, and is still a mystery that needs to be understood. My assumption is that the physical condition of the disease needs to be better understood.

### **Definitions**

For this study, the following terms and definitions are used:

- **Lyme patient** refers to those people that have been diagnosed with Lyme disease and co-infections (Horowitz, 2013; McFadzean, 2012).
- **Lyme disease** refers to the disease transmitted to humans by ticks, mosquitoes, spiders, and deer flies (Horowitz, 2013).
- **Wellness** is an active process through which people become aware of, and making choices toward, a more successful existence (Nationalwellness.org).

- **Community Education** is an opportunity for local citizens, community schools, agencies and institutions to become active partners in addressing education and community concern. It embraces the beliefs that education is a lifelong process, everyone in the community shares a responsibility for the mission of educating all members of the community and citizens have a right and responsibility to link the needs of the resources to improve their community (Unesdoc, 2005).
- **Medical Education** is the clinical practice, teaching, and research that is learned and understood through the telling or receiving or creating of stories (Charon, 2006).
- **Chronic Disease** is a condition lasting three months or more, and cannot be prevented by vaccines or cured by medication nor do they just disappear (Medicinenet, n. d.).

### Chapter Summary

This chapter looked at the background of Lyme disease and the design of this study. The research question and defined terms allow the reader to better understand the outcomes being sought. By understanding the meaning of narrative inquiry and the use of a constructivist stance, the meanings that are interpreted from interviews provide a voice to the participants. Chapter two provides a review of the literature related to Lyme disease and the study to show what research currently exists and where this study fits in the larger academic and medical context.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

*We never had, in the last 5 years, a single MS patient, a single ALS patient, a single Parkinson's patient who did not test positive for Borrelia Burgdorferi . . . not a single one.*

*Dr. Dietrich Klinghardt, MD (Broken, 2015).*

#### **Introduction**

The topic of Lyme disease as a chronic illness can be found within a large amount of literature, however the focus is around how the medical field treats the disease. It discusses the debates regarding the disease and how it is discovered. It exposes the lack of acknowledgement that the disease earns from the government, insurance providers, and organizations that research the disease. My interest, for this study, is the patients themselves and their stories, and in reviewing the literature, there is very little published.

This study is focused around the stories shared of those that have Lyme disease. Because of the breadth of the topic and to maintain a concentrated focus within the topic area of my study, this literature review focuses on key components that are driving this study as it relates to Lyme disease. We will first explore community education and how informal learning is experienced and why it is important to those with Lyme disease. We will then transition to the six dimensions of wellness to show areas that should work together to bring balance to one's life. When out of balance life becomes increasingly difficult as we see when we review narrative medicine and Lyme disease as a whole.

#### **Community Education**

The role of a community educator, as stated by O'Sullivan, Morrell, and O'Connor (2002), is to rethink how we bring about educational change and how to have deep conversations that provide a view of necessity, value, and how to make decisions that affect day-to-day living.

This can be accomplished through informal learning that focuses on academic excellence, diversity awareness, wellness, and meaningful relationships.

By working through five basic concepts of a group, as stated by Butow, Kristen, and Price (2006), participants and leaders evoke stimulation (tactics to engage participation), provide executive management (anything that concerns the workings of the group), produce meaning and attribution (adding meaning, structure or focus of group interactions), insert the use of self-revealing own feelings and personal beliefs, and expression of support and care (offering support, protection or comfort) to assist with the informal learning that takes place through support groups.

A support group allows for safe disclosure of issues to provide participants with support (Bush & Donaldson-Feilder, 2009). A support group affords the participants an “opportunity for reflection on self and process, learning from others, and learning about self” (Bush & Donaldson-Feilder, 2009, p. 37). According to Hart-Smith (1987), a support group provides participants a network of support, and a forum to share problems and solutions (p. 8). It also provides participants the feeling of belonging and close friendship within a supportive environment (Brown & Tregea, 2013).

The purpose of health-related support groups is to help participants manage their chronic conditions by connecting them with peers from similar life circumstances or with similar health conditions (Knox, Huff, Graham, Henry, Bracho, Henderson, & Emsermann, 2015). Within support groups, it is commonly accepted that personal testimonies provide informal learning for all attending. Using the literature, I provide a definition of informal learning within a support group setting, and examine how resources are shared among the group.

## **Informal Learning**

The idea of informal learning can occur within a support group. According to Merriam and Brockett (2007), informal learning is usually unplanned, experience-based, incidental learning that happens during the process of sharing people's daily lives. This allows for learning to take place during casual conversations and the sharing of events that are similar to one another. Huang (2006) identified the informal learning process as the development of skills necessary to discover, retrieve, and manage information needed to make necessary decisions.

Merriam and Brockett (2007) stated that while the structure of a support group is usually setup in a formal learning style and has specialized programs offering technical and professional training, learning also happens more informally. Merriam and Brockett (2007) also considered that the deeper and more meaningful learning takes place during informal and spontaneous, unstructured places within neighborhoods, the workplace, marketplaces, library and museums, various mass media arenas, and meaningful casual conversations. The ultimate outcome is to assist people regarding local issues and critical concerns that they are experiencing. Huang (2006) explained that group members must process, analyze, and synthesize information in order to come to appropriate conclusions and judgments for their situation.

Support groups, while having a formal structure of planning and organization, rely on those attending the group to share their experiences, thoughts, and knowledge base in order to help one another. Molee, Henry, Sessa, and McKinney-Prupis (2011) described that when people share their experiences they learn about their strengths and weaknesses, sense of identity, assumptions, beliefs, and convictions. This process places support groups within the informal learning realm and provides a place for relationships to grow and support to be given by all.

Bush and Donaldson-Feilder (2009) shared that setting up support groups are pragmatic and lead to reflective learning. They go on to say that the formation of support groups allows participants to assess meeting content and outcomes in relaxed and supportive environments. Hader (2005) shared that critical thinking (reflection) provides a more insightful understanding of yourself and allows for an opportunity to be objective, less emotional, and more open-minded as you work with others experiencing the same issues. Participants reflect on their own needs, question standards and practices, and develop relationships thus learning about themselves and others within the same situation.

### **Resources Shared**

Hansman (2016) wrote that informal learning is the natural accompaniment to everyday life and that sharing resources are essential when setting up and conducting support groups. By sharing items like pamphlets, website designs, guest speakers, funding, and Board of Directors, as experienced through a Lyme support group, multiple people in multiple locations can be served.

Roberts (2008) recognized that it does not matter where people are in the process of an illness or issue, everyone is perceived as having knowledge and sharing resources provides context in a consistent manner. When resources are shared, the ability to answer questions and to form collaborative cohorts become the center of the group. According to Solomon, Pistrang, and Barker (2001), one important coping resource that is shared is social support. Social support includes practical help, information, and emotional support, which can encourage feelings of normality. Roberts (2008) also stated that learning is contextual and does not take place in linear sequence, it is an ongoing process of sense making.



## **Social and Ethical Responsibilities of Community Educators**

Community educators, also known as advocates (Hatcher & Storberg-Walker, 2003; Cohen, 2004), have a history of promoting positive learning by advancing community, promoting academics, encouraging diversity awareness, promoting wellness, and cultivating meaningful relationships (Waghid, 2007; Lough & Thomas, 2014). Community educators are creative in the way in which information is disseminated. Community educators feel a responsibility to help people envision and enact global learning, questioning diversity, identity, citizenship, interconnection, and responsible action (Hovland, 2009).

Henton, Melville, and Walesh (2014) shared that community educators have a social responsibility to create networks in ways that reengage citizens in their communities. Having a passion to help others, and wanting to share knowledge to strengthen a community leads to an ethical responsibility to promote safe environments to have dialogue. Clark (1993) stated that ethics and social responsibility is a goal of promoting human welfare as well as an obligation to cultivate relationships to improve the quality of life.

Community educators encourage learning through participation and knowledge sharing to master skills to which those within the community wish to learn (Yuan, Gay, & Hembrooke, 2006). Kakkad (2005) reflected that when learning takes place in a collaborative environment communities are open to developing new conceptualizations of how individuals, families, and communities are being impacted on multiple levels thus creating trust and encouraging growth in all participating.

Community educators provide diverse knowledge, experience by practice, and an understanding of how to think about practical situations. According to Hatcher and Storberg-Walker (2003), this cultivates a need for ethics that are generated from individual values and

beliefs to produce high-quality outcomes. Community educators encompass characteristics of integrity, fairness, communication with ethical standards, and show empathy for others, and share power (Schwartz, 2015).

Schwartz (2015) wrote that community educators are honest, fair, principled, and trustworthy, and she suggests that people learn what to do by modeling behaviors, listening and observing others. They display a principle of ethics model: doing no harm, being honest, allowing people to make their own choices, doing good, promoting well-being, keeping promises, and showing fair treatment (Chapin & Byrne, 2013).

As community educators work within the community they provide support and encouragement. Deggs and Miller (2011) identified a community as a group of people who have something in common with each other. This community understands how their actions and their existence impact development of individuals by providing life choices (Deggs & Miller, 2011) through experience. The community educator values self-exploration, development, and formal and informal learning (Deggs & Miller, 2011). These social and ethical responsibilities promote a desire to engage in creative activities, promote healthy living habits, and develop a sense of pride throughout the community they serve. Deggs and Miller (2011) and Kakkad (2005) continued by saying that the community educator raises important and challenging questions to build upon experiences, thus contributing to the integrity of the community.

### **Six Dimensions of Wellness**

Charon stated, “That medicine grapples with the relation between body and self in health and illness” (2006, pg. 86). Illness intensifies what is valuable in life, which relationships are most meaningful, what terrors or comforts the end of life holds (Charon, 2006), and where balance is being compromised. The six dimensions of wellness, as stated by Hettler (1976) is a

model that shows balance within six critical points of one's lives. It provides a holistic view allowing patients of Lyme to focus on specific areas. As we weave the stories and journeys of the participants into the dimensions, and induce them into the categories, themes will emerge to show that Lyme patients and their supporters lose balance. The figure shown below identifies the six dimensions of wellness.



**Figure 2:** Hettler, B. (1976). *The Six Dimensions of Wellness*. Retrieved from [nationalwellness.org](http://nationalwellness.org)

With the vast amount of information discovered it was decided to utilize the theoretical framework of the six dimensions of wellness to observe the experienced phenomenon of Lyme disease and how it disrupts the balance of wellness. The model, made up of six areas: occupational, physical, social, intellectual, spiritual, and emotional, incorporates balance; and according to Adams, Bezner, Drabbs, Zambarano, and Steinhardt (2000) seeks to assist individuals to survive and thrive under conditions of extreme stress.

Adams et al., (2000), shared the definitions of the dimensions:

- Occupational is the perception that one will experience positive outcome through events and circumstances within their work life.
- Physical is the perception and outcomes of physical health.
- Social is the perception of having support from family or friends.
- Intellectual acknowledges the perception of optimal learning through stimulating activity.
- Spiritual possess a sense of the meaning and purpose of life.
- Emotional is a secure self-identified positive sense of state of mind.

With these definitions in mind, and understanding some of the history of Lyme, it becomes concerning how a person with Lyme disease finds balance. As we look at the literature for each dimension, the realization becomes clear that there is little balance within a Lyme patient's life.

### **Occupational Wellness**

According to Piacentino and Schwartz (2002), Lyme disease has been documented in occupation groups such as forestry workers, farmers, veterinarians, military recruits, orienteers, and outdoor workers. When the person is infected, and if not treated, they report impaired functional mobility in activities and daily living (Moser, 2011, p. 1414), thus making the person unable to work and in some instances, lose their employment. This makes sense as ticks and other Lyme carrying insects most generally live in the outdoors. These outcomes do not seem to fit within the definition discussed above. Losing or having to quit a job does not promote positive events and thus leads to an imbalance within their life.

## **Physical Wellness**

The perceptions of physical wellness are usually based on what the naked eye can see. When one meets a person with Lyme disease, Horowitz (2013) stated they do not normally look ill, but according to McFadzean (2012), in most instances they are suffering terrible pain feeling like death warmed over. Ali, Vitulano, Lee, Weiss, and Colson (2014) stated that people with Lyme disease described themselves pre-Lyme as athletic, healthy, never sick and energetic. Then, normally without warning, they can no longer work out and are so fatigued they can no longer function.

Other outcomes that show there is little physical wellness was stated by Paparone (2016) sharing that most people with Lyme disease experience flulike symptoms – fever, chills, swollen glands, fatigue, headache, stiff neck, sore throat, backache, muscle aches, nausea, and vomiting. Horowitz (2013) shared that Lyme patients also experience cardiac problems, neurological problems, Bell's palsy, nerve palsy, cardiac disease, meningitis, joint pain and arthritis. Aucott, Rebman, Crowder, and Krotte (2013) also stated that neuropathy, memory deficits, concentration difficulties, cognitive dysfunction, and musculoskeletal pain create additional issues for those with Lyme. These factors do not promote balance.

## **Social Wellness**

Humans are relational creatures according to the New International version of the Bible. Romans 12:4-5 indicates that people need to be with people. Because of the physical issues that people with Lyme experience McFadzean (2012) shared that Lyme patients feel very isolated, misunderstood, and alone in their illness. They are afraid to make plans because there is a very real possibility that they will have to cancel. The reasons are numerous and this brings on depression and other psychological issues.

Social activities are not the only area that experience issues of isolation. Ali et al., (2014) shared that there are professional limitations with prolonged absences from work. Social limitations, including feeling isolated, not being understood, or others not believing that they are ill are experienced regularly.

Creating balance within this dimension requires support from close friends and family. Dr. Horowitz (2017) shared that most relationships will not last through the struggles of healing Lyme disease, but if they do their connection will be strong.

### **Intellectual Wellness**

Learning to live with Lyme requires activities like support groups to be formed. These groups educate people, according to Paparone (2016), on how to eat, according to McFadzean (2010), to support the immune system – detoxification – and what foods create reduced inflammation, ways to remove a tick properly, help with working within the disease, but most importantly support groups teach people how to communicate with their medical professionals.

Speaking to medical professionals is also a stimulating activity. Meaning that everyone, patients and doctors, are still learning about Lyme disease. According to Nadelman and Wormser (2007), there are multiple measures to limit exposure to ticks including covering bare skin and using tick repellents. The issues then get to be that blood tests and areas of diagnostic processing do not seem to be available, thus according to Wright and Mervin (2000), leaving doctors with a sense of ignorance about diagnosis, treatment and procedures for treating the disease.

### **Spiritual Wellness**

Watson (1985) described spirituality as involving unity and harmony within the mind, body, and soul. McSherry and Draper (1998) shared that spirituality is intimately interlaced

within healthcare issues and is fundamental to human existence as well as survival. Nolan and Mauer (2006) discussed the idea that to have a sense of meaning and purpose within one's life, especially with a critical illness, that knowledge, attitudes, and behaviors are critical. Therefore, it is perplexing as to why, throughout the literature, there is little discussion about spiritual wellness as it relates to Lyme disease.

The other side of spiritual wellness focuses on a religiousness that assists patients with chronic illness as a way to manage symptoms. Rowe and Allen (2004) shared that strong religious beliefs have proven to decrease pain, hostility, and social isolation, as well as produces high levels of life satisfaction and lessens depression.

### **Emotional Wellness**

The emotion within this dimension states that people should have a self-identified positive sense of state of mind. This is not normally the case as Ljostad and Mygland (2012) outlined that many Lyme patients are confused and have feelings of being misdiagnosed, mistreated, and discouraged. Barinaga (1992) shared that doubt, fears, and anxiety runs high within emotions of Lyme patients.

The other side of emotional wellness, or un-wellness, that Lyme patients deal with is two-fold. First, Wright, and Mervin (2000) shared that several Lyme patients report that their doctors do not believe that this critical disease exists. This lends itself to the second and what Ali et al., (2014) shared that patients with Lyme disease are fearful that they might die from the disease or that the patients have had suicidal thoughts. Neither fits into the definition of emotional wellness.

## **Meaning of Wellness**

While the idea of wellness works toward life balance in all areas, Lyme patients and their supporters rarely experience this. Adegbola (2006) shared,

The subjectivity and multidimensionality of individual's spiritual needs result in a phenomenon that is not clearly understood by others, as the individual adapts to disease and illness burden. The adaptation of the individual to a gap existing between expected and actual functional states may have health policy implications . . . all providing prognostic input regarding survival and well-being. (p. 42).

Therefore, appraising all domains of one's life provides a guide for diagnosis, treatment, and healing. At times, this becomes the only hope that patients and supporters experience for years.

## **Narrative Medicine**

Considering the idea of components of wellness leads to the importance of narrative medicine, a practice that reshapes dialogue with medical professionals and people with Lyme disease. Mahr (2015) wrote that humans encounter themselves and each other by dealing with illness and suffering through story or narrative. By capturing the experiences through different stories new freedoms, choice, and meaning can be given to the medical condition. Mahr (2015) shared that "people act on the basis of meaning, the constellation of ideas and interpretations people have about what is going on" (p. 505). These stories, as told by those living with the experience, are neither true or false but rich and meaningful.

Narrative medicine, according to Mahr (2015), acknowledges the power in the doctor-patient relationship role. This role indicates that doctors have power and that the narrative



acknowledges the reality. By sharing their stories patients balance the power by being genuine, more authentic, and truly owning their experiences; and by sharing become aware of how their stories affect self and others.

### **Chronic Disease**

Chronic disease is defined by Medicinenet (n. d.) as a condition lasting three months or more, and cannot be prevented by vaccines or cured by medication nor do they just disappear. Chronic diseases are known as diabetes, heart disease, lung disease, HIV/AIDS, and some forms of cancer, to name a few. Lee, Piette, Heisler, Janevic, Langa, and Rosland (2017) shared that people with chronic health conditions benefit from an array of professional services like self-management classes, health education, and professional consultation to maintain daily functions.

Literature shows that people with chronic diseases create new norms within their daily lives. Snelgrove, Wood, and Carr (2016) supported this by stating,

In the case of chronic illness, disruptions to individuals' leisure involvement and experiences may occur because of illness related physical restrictions or symptoms, a lack of suitable opportunities, low self-esteem, difficulty fitting-in, social exclusion, and negative social interactions. (p. 34).

Kelleher (1988) mentioned that people with chronic illness follow medical advice and adhere to treatment to control their disease, but by doing this a feeling of loss of freedom and control over their lives is felt. Heaton, Raisanen, and Salinas (2016) stated that the loss of control over one's life, with a chronic disease, leaves the patient without balance of their health and overall well-being.

## **Lyme Disease**

Lyme disease is a multifaceted illness that has many health effects on the human body. It can take on various forms depending on the host; this makes it very difficult to diagnose and identify. The disease of Lyme, or at least different parts of Lyme, were discovered by different people at different times. McFadzean (2012), shared,

Often cited that the first cases of Lyme disease originated in a specific region in Connecticut in 1975 . . . However, descriptions of the illness that is now known as Lyme disease date as far back as 1764. Reverend John Walker was visiting an island off the coast of Scotland, and documented an illness with severe pain in the limbs that he related to a tick vector . . . In the 19<sup>th</sup> century, the examination of preserved museum specimens found *Borrelia* DNA in an infected *Ixodes ricinus* tick from Germany that dated back to 1884, and from an infected mouse from Cape Code that died in 1894. (p. 19)

Lyme, with its multisystem tick-transmitted disease causes spirochete *Geno* groups and *Borrelia burgdorferi sensu lato* (Fallon, Pavlicova, Coffino, & Benner, 2014) which causes an illness that is hard to detect and masks itself as several other problems. This means nothing to anyone until one looks at those that have become infected, their symptoms, and the treatments they have experienced or continue to endure.

### **Infected**

Humans, most generally, become infected with Lyme disease from May through August, when both they and the nymph ticks are active outdoors (Chaaya, Jaller-Char, & Ali, 2016). Additionally, in 2001, Armstrong, Brunet, Spielman, and Telford III indicated that people reporting a history of Lyme disease were more likely to garden, experience more than one tick

bite per week, or neglect to use personal protection measures, which results in chronic Lyme because of the gestation period of the disease.

But how does one know if they are infected by this tiny, almost invisible insect? Aucott et al. (2012) stated that people report the presence of an average of one medical diagnosis, such as Hypertension, Thyroid Disease, or Hyperlipidemia, and typically are experiencing limitations in health functions. Yet in 2013, Levy stated that Lyme disease symptoms can include rashes, fevers, joint and muscle pain, and heart as well as neurological problems, and Pauldine (2003) further acknowledged that if tick bites are not treated early then severe arthritic, neurologic, and cardiovascular symptoms can appear.

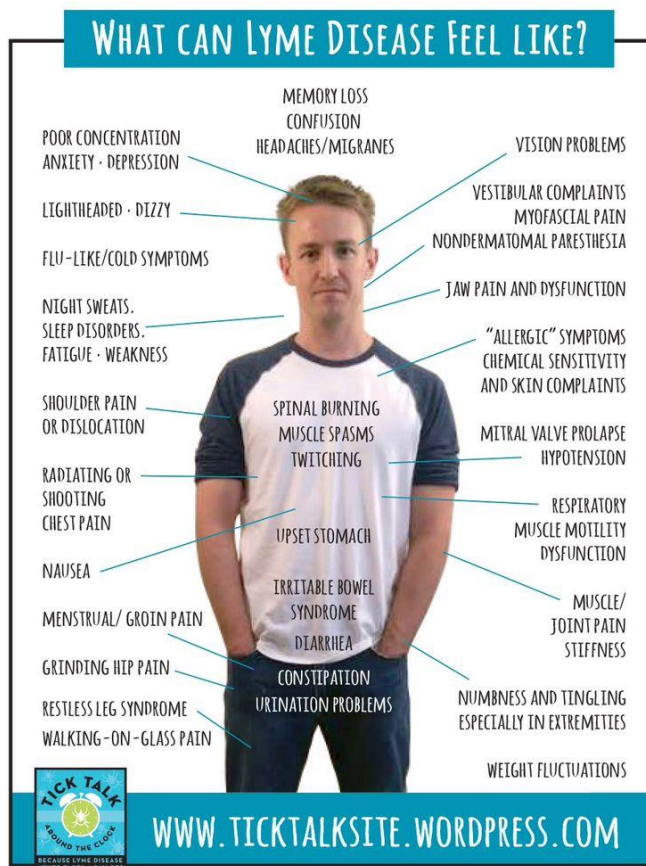
The symptoms are numerous as, “patients with erythema migraines and underlying hematological malignancy more often had signs of disseminated Lyme borreliosis” (Maraspin, Ruzic-Sabljić, Lusa, & Strle, 2015, p. 427). If not treated early the disease reaches a chronic stage that then produces other symptoms. Chaaya et al. (2016) stated, “Chronic Lyme disease can often share somatic symptoms with other conditions such as Fibromyalgia, Chronic Fatigue Syndrome, and Irritable Bowel Syndrome” (p. 375). Hu (2016) went on to say that “Chronic Lyme disease most commonly refers to continuation of such symptoms as fatigue, myalgia, arthralgia, memory loss, and headaches” (p. ITC78).

## **Diagnosis**

Once symptoms appear, how does one obtain a diagnosis? Testing for Lyme disease relies predominately on the examination of blood serum. The recommendation is to look first at the enzyme-linked immunosorbent assay (ELISA) and, if positive, is followed by a supplemental Western Blot blood test (Hu, 2016). The picture of complex clinical results compounded by a history of inconsistent laboratory tests and lack of a standardized diagnostic definition (Rowe,

2000) means that there is confusion within the medical field and uncertainty within the patients. Therefore, when a diagnosis of chronic Lyme disease is given, it provokes considerable confusion, fear, and anxiety (Lantos, Shapiro, Auwaerter, Baker, Halperin, McSweeney, & Wormser, 2015). Keep in mind that a single diagnosis produces other questions and Lyme disease, because of late manifestations, can occur one to two months or months to years after tick exposure, this results in substantial morbidity (Chaaya et al., 2016).

These “Conditions of Lyme disease can fit into one of three stages: early localized, early disseminated, and late persistent” (Pauldine, 2003, p. 50). For clarification, the stage of early localized Lyme disease is from the time of bite to several months later, and early dissemination Lyme disease is considered as stage two and it can begin as early as one month to years later. Early dissemination is where physical, mental, and flu like symptoms begin to be persistent. Late persistent Lyme disease is chronic stage where symptoms have been untreated for years (WebMD, 2014). By the time most people start having symptoms, Patrick, Miller, Gardy, Parker, Morshed, Steiner, Singer, Shojania, and Tang (2015) stated that patients report the potential of not being able to meet the demands of a full-time job, sleep disturbance, and profound fatigue and experience difficulties with healthy controls such as depression, memory loss, and physical issues.



**Figure 3:** Lyme. (n.d.). *What can Lyme disease feel like?* Retrieved from [ticktalksite.wordpress.com](http://ticktalksite.wordpress.com)

## Treatment

Treatment methods can range from antibiotics to unorthodox holistic solutions. An interesting fact was reported in 2006 by Nolan and Mauer, “In 1998, the Food and Drug Administration licensed the vaccine LYMERix. The vaccine did not provide 100% protection from Lyme disease, even after the complete three-dose regimen” (p. 379). Pauldine (2003) went on to say that “LYMERix was removed from the market in February 2002 because vaccinated patients complained of developing arthritis. Another vaccine, ImuLyme is awaiting approval by the Food and Drug Administration” (p. 52). While antibiotics appear to work for early stage Lyme disease, for post-Lyme disease syndrome antibiotics are not recommended (Chaaya et al.,

2016) allowing other treatment methods to be introduced to patients. These treatments consist of herbs and natural non-synthetic materials, Reiki, a process which uses natural oils and crystals, and Ozone which is an “Oxygen therapy [that] was marketed to patients for treatment of Lyme disease primarily in three forms: hyperbaric oxygen, ozone, and hydrogen peroxide” (Lantos et al., 2015, p. 1777). These alternate or unorthodox treatments, according to Lantos, Shapiro, Auwaerter, Baker, Halperin, McSweeney, and Wormser (2015), indicate that alternate therapies without direct adverse effects, may delay the identification and treatment of the diagnoses. This may also come at significant financial cost to the patient.

As the debate around Lyme disease continues, people are becoming more and more vocal. Lantos et al. (2015), found “The easy accessibility to testimonials from patients, particularly in the forms of online blogs, discussion boards, and promotional materials by alternative therapy providers, can be persuasive to vulnerable populations” (p. 1779). Patients with this diagnosis are important for providers of alternative medicine. Many patients are without doubt suffering from chronic, often disabling symptoms, regardless of whether their diagnosis of Lyme disease is accurate (Lantos et al., 2015).

As the symptoms of Lyme disease became more critical within patients, Horowitz (2017) stated that other chronic illnesses were experienced: Tuberculosis, Syphilis, Hepatitis B, Hepatitis C, HIV, and Rocky Mountain spotted fever. These diseases became known as co-infections causing chronic illness to be experienced within Lyme patients.

When a person is bitten by a tick and it is not noticed, the spirochete enters the blood stream and Lyme disease occurs. Keep in mind, as stated by Horowitz (2013), that spiders, mosquitos, and deer flies can transmit the spirochete, along with ticks. According to McFadzean (2012), Lyme disease is identified within three categories: early localized, early disseminated,

and chronic Lyme. Within each stage symptoms compound and worsen, treatments work and then they stop, and each day brings new challenges and new pain.

Buhner (2013) shared that there are many different types of treatment. Some patients use and respond to antibiotics while others have to focus on holistic approaches because their system cannot handle the severity of the medications. Thomas Edison spoke to this in his profound statement toward this disease, “Until man duplicates a blade of grass, nature can laugh at his so-called scientific knowledge . . . it is obvious that we do not understand one millionth of one percent about anything” (Buhner, 2013, p. 46).

The research that currently exists about Lyme disease focuses primarily within the medical field, ongoing symptoms, antibiotic therapy, re-treatments, and clinical improvement (McFadzean, 2012). There is very little literature about the experiences of those who live daily with Lyme disease, and even less about those who support people with Lyme disease. Research is beginning to show that Lyme disease is the fastest growing epidemic in the world (Horowitz, 2013; McFadzean, 2012), and therefore, voices of the ill need to be heard, so that the medical field will take notice.

### **Chapter Summary**

The literature for Lyme disease is vast in accordance with the history and medical treatments. There, however, is a huge gap within the literature of actually hearing the voices of Lyme patients. We discussed the background of Lyme disease and looked at how Lyme disease disrupts the balance of the six dimension of wellness. These dimensions are designed to be positive when dealing with wellness, but what was discovered is that there is very little positivity within the Lyme community and the Lyme literature. Chapter three will describe the tools and methods that I will use for this research study.

## **CHAPTER THREE**

### **METHODS**

*When you have been trained in a particular medical specialty, you see the world through certain lenses and diagnostic paradigms.*

*Richard I. Horowitz, MD (2013, p. 22)*

#### **Introduction**

To understand the experiences of Lyme patients, I conducted a study using narrative inquiry. As subjects' stories unfolded a sense of self and the identity they share was heard. Through re-presentations of the stories shared, permission is given for interpretation and co-constructed knowledge to emerge (Creswell, 2013). This provided a sense of collaboration and healing through the knowledge that one is not alone. When people experience life changing events, they need to reflect on those moments as a way of "recognizing, absorbing, and interpreting" (Charon, 2006, p. 4) that which has happened to them.

#### **Qualitative Research**

Qualitative research identifies descriptions of incidents, actions, and processes (Russ-Eft & Preskill, 2009) and requires in-depth analysis and coding of data. Denzin and Lincoln (2011) stated that qualitative research is the study of things within their natural settings, attempting to make sense of or interpret a phenomenon by the way that people bring meaning to them.

Qualitative research is a collection of materials – case studies, personal experiences, introspections, life stories, interviews, and artifacts (Denzin & Lincoln, 2011). Researchers immerse themselves through observation, focus groups, and semi-structured interviews, all while making the participants' world visible (Denzin & Lincoln, 2011).



Denzin and Lincoln (2011) expressed characteristics of qualitative research as narrative, archival, and phonemic analysis utilizing techniques such as ethnomethodology, phenomenology, hermeneutics, feminism, deconstructionism, ethnographies, and many others. The emphasis on these entities construct a nature of reality and express an intimate relationship (Denzin & Lincoln, 2011) between the researcher and the participant. Qualitative research seeks to share stories and experiences through feelings, passion, and thoughts of people (Creswell, 2007; Maxwell, 2005; Merriam, 2002). Researchers then develop theories from these experiences through inductive and deductive reasoning (Merriam & Simpson, 2000).

Strengths of qualitative research, according to Creswell (2013), include exploration of problems or issues, empowerment of individuals to share their stories, flexibility within the style that information is shared, and it helps explain causal theories or models. As the researcher, I sought to answer questions that stressed how social experience was created and given meaning (Denzin & Lincoln, 2008, p. 14). Additionally, Denzin and Lincoln (2011) stated that strong characteristics of qualitative research include accepting postmodern sensibilities, capturing the participants point of view, examining the constraints of everyday life, and securing rich descriptions, all while constructing knowledge. Creswell (2014) shared that qualitative research is conducted in natural settings, the researcher is the key instrument, researcher uses multiple sources of data, researchers can utilize inductive and deductive data analysis, researcher gives meaning to the participants, reflexivity helps provide themes, and the holistic approach develops a picture of the problem.

In order to determine the design of the study, I needed to identify goals, research questions, and identify the framework to obtain data (Maxwell, 2005). According to Crotty (1998), theoretical perspective has an understanding and stance regarding methodology and an

epistemology that embeds knowledge within the theoretical perspective. This interconnectedness allows the participants voices to be heard. As the relationship between researcher and participant grows, meaning that is constructed is transmitted through the participants' response into and through the research, as an instrument. As the inductive process occurs and themes are identified, the next step is to look back and deduct to see if additional themes emerge (Creswell, 2014).

Weaknesses of qualitative research include a requirement of extensive time in the field, and there is complex and time-consuming data analysis (Creswell, 2013). Leavy (2014) discussed the need to ensure ethical regulations since stories that are shared can cause pain, emotional distress, and other potential threats. Because some researchers feel that qualitative research lacks accuracy and rigor (Leavy, 2014), they are marginalized at times.

### **Research Question**

Hatch (2002) believed that a research question is central to the process; but should not be the starting point. Therefore, to discover the essence of Lyme disease and what my participants experience, this study will focus on:

How do the participants narrate stories about their experience living with Lyme disease?

### **Narrative Research**

This study sought to answer the research question and begin to develop an understanding of Lyme disease. The qualitative research approach used, narrative inquiry, is composed of “affective, emotional, and often intense human experiences” (Merriam, 2014, p. 26). Hatch (2002) shared that when research is focused on gathering and interpreting stories that people use to describe their lives, narrative research should be considered. Clandinin and Connelly (2000) expressed that when researching a problem, we must think of the wholeness of an individual's

life experience. “Life is filled with narrative fragments, enacted in storied moments of time and space, and reflected upon and understood in terms of narrative unities and discontinuities”

(Clandinin & Connelly, 2000, p. 17). Vagle (2014) wrote that we find ourselves in relation with the world through day-to-day living, and this is when stories are shared and relationships are built.

Creswell (2013) stated that narrative research is a history of personal reflections of specific events that are shared through conversations that researchers and participants engage in. Clandinin and Connelly (2000) shared that narrative studies do not follow a rigid approach, but it represents an informal collection of stories.

Narrative research, according to Creswell (2013), works best for capturing detailed stories of life events by spending considerable time gathering stories. The researcher collects information from participants within their natural settings. Then the researcher transcribes and reads and re-reads the information for themes and to better understand what was shared, (Creswell, 2013). As part of this research, I also reviewed my journal entries, observations and field notes to interpret the participants’ stories. Many approaches and avenues can be used to share the stories, and for this study, poetic storytelling was used.

Narrative research has different approaches. Hatch (2002) suggested using narrative inquiry through and narrative ways of knowing to seek and capture storied knowledge. The idea for this type of research is that “the emphasis is on the meanings individuals generate through stories, and constructivist researchers and their participants co-construct the stories that are told as part of the research” (p. 28).

Clandinin and Connelly (2000) wrote,

Narrative inquiry is a way of understanding experiences. A collaboration between researcher and participants, over time and in places . . . It's in the midst of living and telling, reliving and retelling the stories of the experiences that make up people's lives that provide meaning. (p. 5).

All of this to say that the purpose of this study is to understand how people experience Lyme disease through daily actions, decisions made, and stories told.

Narrative inquiry, according to Clandinin and Connelly (2000), captures personal and human dimensions of experience over time, and takes account of the relationships built from individual's experiences. This means that narrative inquiry is a way in which the researcher can systematically gather, analyze, and represent participants' stories in their own voices. Clandinin and Connelly (2000) expressed that these stories challenge traditional views of truth, reality, knowledge, and personhood.

Narrative inquiry provides us with Polkinghorne's (1995) view of narrative knowing which creates and constructs the stories through experiences (Clandinin & Connelly, 2000). The stories allowing for creation of meaning and the ability to help make sense of ambiguity and complexity of the experiences within human lives (Hatch, 2002; Leavy, 2014). Narrative knowing allows the researcher to bring together layers of understandings about people, so that their struggles can be heard and meaning can be made. By shaping stories through interviews, observations, and reflexivity, the story of Lyme disease can be shaped by understanding the participants' values, beliefs, and experiences to guide interpretations, and raise up their issues and hopes (Clandinin & Connelly, 2000). Hearing descriptions that construct and reconstruct the impact of Lyme disease is a way to gain knowledge and hear multiple voices, perspectives, truths, and meanings.

Many people that are chronically ill have the innate ability to share their stories while recognizing the need to educate those around them. Charon (2006) shared that there is no representation of a story the repeats and the delivery of what is being told can be structured originally and irreproducible through poetry. Faulkner (2009) stated, “Good poetry makes a connection to fear – the basic emotion – fear of being the other, learning to not fear” (p. 50), and addresses large issues.

Poetry is an interpretation through the lenses of experience from the researcher meaning that the participants’ stories are recounted in a manner that expresses feelings, emotions, facts, and observations that the researcher found critical. The ideas, words or phrases, as shared by Faulkner (2009), described a seemingly impossible task for a highly personal experience. The goal of writing poetry is to write like yourself but to ensure that the voice of the participant is heard. To determine the best type of poetry many different types were read about and practiced by using one of the interviews. From this process it was determined that free verse poetry was used. Faulkner (2009) shared that free verse poetry allows for creation of your own rules for how a poem should look, and how it represents individual thought and breath patterns. The poem allows participants’ words and questions to contribute to and constrain their identities.

This narrative inquiry study was designed to hear the experiences, through stories of those living with Lyme disease. The participants told their stories, through a semi-structured interview protocol, where questions were asked in no specific order, allowing for conversation to be guided as appropriate (Savin-Baden & Howell Major, 2013). The showcasing and analysis of their experiences honored their journeys and allowed new knowledge to emerge. The study provided new insight to be provided for others either with this disease and offering guidance and support for those that may have been misdiagnosed.

## **Research Design**

### **Narrative Inquiry**

After a thorough review of these different research methods, I chose narrative inquiry using poetry to share the findings. This method allowed for “collaboration between researcher and participants, over time, in a place or series of places, and in social interactions with milieus” (Clandinin & Connelly, 2000, p. 20). Narrative inquiry, as understood by Clandinin and Connelly (2000), follows a recursive, reflective process and is a way of thinking about and studying experiences while maintaining a high standard of ethics.

Clandinin and Connelly (2006) defined narrative inquiry as,

People sharing their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experiences of the world is interpreted and made personally meaningful.

Narrative inquiry, the study of experience as story, then is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the phenomenon. To use narrative inquiry methodology is to adopt a particular view of experience as phenomenon under study. (p. 375).

Through narrative inquiry there are three dimensions that are shared and need to be simultaneously explored: temporality, sociality, and place (Clandinin & Connelly, 2000). Temporality points toward the past, present, and future of people, places, things, and events that are being studied. Carr (1986) expressed this by saying that “we are composing and constantly revising our autobiographies as we go along” (p 76). Sociality is defined by personal and social conditions that are realized simultaneously. Personal conditions include feelings, hopes, desires,

aesthetic reactions, and moral dispositions. Social conditions are both cultural and social narratives, as well as drawing on the connection between the researchers' and participants' lives. Finally, place is defined as "the specific concrete, physical and topological boundaries of place or sequences of places where the inquiry and events take place" (Clandinin & Connelly, 2006, p. 480).

### **Narrative Knowing**

Clandinin and Connelly (2000) shared that narrative inquiry moves between internal and external worlds of the storyteller, across time, within their environment to produce narrative knowing. The conversation expresses a journey that is difficult and time-consuming to recount. This creates, at times, an intense dialogue as participants are asked to share their stories by responding to semi-structured interview questions and by sharing artifacts that trigger memories and deeper dialogue. Craig and Huber (2007) emphasized potential tensions from the beginning of the research process. Nelson (2008) expressed that although there are tensions hearing and understanding these stories are critical to knowledge gathering and sharing.

The process taken for this research was conducted as follows. After multiple interactions with a Lyme support group, friendships began to emerge. During one of the support sessions I was asked to share about my Lyme journey and to also share what I had decided to write about to complete my educational journey. The leader of the group allowed me a platform to invite the population with whom I had already cultivated relationships to become my research participants. Because of the existing relationships the conversation was very comfortable and when asked to speak openly and thoughtfully about their experiences there were many people willing to share. After the session ten people approached me to ask if they could be part of the study. After exchanging phone numbers and emails, with the promise to make contact, the meeting ended.

These potential participants were then called or emailed to setup a time to be interviewed. From the ten potential participants, I ended up setting interviews with eight people. The interviews were scheduled for one hour, at an agreed upon location close to the participants. These locations included private library rooms and home offices.

Interviews began with asking if they were comfortable with our interview being recorded. Then, after confirmation, there was a review and signing of a consent form and finally semi-structured interview questions were asked to assist participants in sharing their stories. At the end of each interview, it was determined that a follow up interview would be scheduled if a more in-depth conversation was needed. Once I returned to my home office, the recorded interview was sent to Rev.com for transcription and the notes were filed within Box on secure servers.

Once transcripts were returned from Rev.com, I read and re-read the transcriptions. This practice allowed for clean up or unnecessary words allowing for the participant's story to be heard. While reading I was looking for any word or phrase that showed the Lyme patient being out of balance. I was specifically looking for ways in which they were struggling occupationally, physically, socially, intellectually, spiritually, and emotionally and more importantly if there were struggles in multiple areas. During this process I found that every participant was suffering in multiple areas and I also found that they were struggling dietetically and financially. While these two additional topics might fit within the large topics identified within the six dimensions of wellness there was such specificity and discussion about the two additional that I felt like they needed to be added as their own categories.

Reflecting on my notes and journal entries, as well as re-reading transcripts the idea to create a poem so participant's voices could be heard clearly and emotionally was decided upon.



This process was put in place so each person's story could be shared with their words through my interpretation.

### **Trust and Openness**

Merriam and Simpson (1984) shared that research is frequently categorized as a source of truth used within our quest to know. The truth is discovered by what Hatch (2002) described as knowledge that is uncovered through using participants that are making sense of their own culture. Trust and openness are critical since narrative inquiry shares lived stories. The process for this is relational and requires agreed upon considerations.

Clandinin and Connelly (2006) stated that it is essential to think about the phenomenon through the inquiry from start to finish. Keeping the phenomenon in the forethought highlights the shifting, changing, personal and social nature and challenges the story throughout the inquiry. This influences self and others and it becomes "a sense of a search, a 'research,' a searching again", "a sense of continual reformulation" (Clandinin & Connelly, 2000, p. 124).

I shared the processes that were taken for this study in an open and honest manner through my signed consent form. This form outlined the methods for data collection as being one hour interviews with follow up interviews as needed; and for transcription of these interview through Rev.com thus allowing the participant to choose their participation. Additionally, keeping the phenomenon of Lyme disease as our topic of conversation was essential. There were times of expressed understanding and agreement since I have personal experience with this disease as well.

Interviewing participants was difficult for me because of my understanding of their journeys. In order to ensure that I maintained a clear and unbiased thought process, Rev.com was used. Once the transcripts were returned I read and re-read to re-engage with the content.

This was a painful process, but choosing these steps provided needed balance of self with the research.

### **Ethical and Critical Engagement**

When working with people who are diagnosed with Lyme or another chronic disease, there are additional ethical issues to explore. Josselson (1996) posed questions that we should ask ourselves: Do you really feel like interfering in his or her life? Will you be able to live with the consequences? Noddings (1986) introduced “fidelity to relationships” (p. 647), as it is the responsibility of the researcher to maintain an ethical code by doing no harm, having a learning attitude of empathy, and by not being judgmental to the participants’ stories.

As the researcher, I protected the identities of the participants through using a collective voice of commonalities through these stories. The use of poetic form provided anonymity for the participant, but still shares the emotion and context of their experiences.

### **Poetic Storytelling**

To make sense of the stories shared and to allow for the collective voices of all participants to be heard, poetic storytelling will be used. Poetry, according to Faulkner (2009), makes the invisible world visible and has the ability to clarify as well as magnify experiences. Experiences shared can be interpreted via poetry. Faulkner (2009) shared that narratives of self can be messy and because multiple voices contribute, poetry allows a space for no one interpretation to stand out more than another. Faulkner (2009) continued by stating,

The researcher can use phrases from interviewees anywhere in the transcript and juxtapose them as long as they were the interviewee’s words and enough words were presented to mirror the participant’s rhythm and way of speaking. By reading and re-reading the interview transcripts, and at the end themes that

described different aspects of the interviewee's life are used, poetry can be created and shared. (p. 31).

Additionally, Faulkner (2009) acknowledged that research poetry is designed to experience connection with participants through an emotional response. The underlying idea is that readers and listeners, although not experiencing the same disease, can share the experience through an emotional connection with the descriptions and depictions displayed in poetry.

A good poem, according to Faulkner (2009), is like the development of love. It starts in your gut; you fall in love with it, then you start to care how it's made. The poems created should connect to the issue and should make the listener or reader feel emotions such as anger, joy, hope, and so much more.

Crafting research poetry interprets the interviews in order to tell a powerful version of experiences communicated. Faulkner (2009) shared that the writer uses punctuation as desired for outcome, uses recurring lines to create continuity, and allows freedom in design. As the interviewee's words were read for themes, I sought out the "essence conveyed, hues, and textures" (Faulkner, 2009, p. 134).

### **Storyteller, Both Voices Heard**

Faulkner (2009) adopted poetic inquiry as a term to provide poetic forms within narrative inquiry. The narrative poem allows for storytelling from collective interviews and represents actual experiences that, according to Faulkner (2009), allows distance between self and others to blur, while allowing others to feel episodes, epiphanies, misfortunes, or pleasures. Clandinin and Connelly (2000) described the link between the researcher who hears and recounts the story,

with the participant who tells the story, who are both engaged in the phenomena. This link makes it possible to advocate for social change and shift social and cultural narratives.

In this study, I used poetic storytelling to share themes through the collective voices of the participants. Continuing the ethical and critical engagement that allowed for participants' identity to be unidentifiable while sharing their experiences of Lyme disease to help make sense of stories shared.

While thinking through content of shared stories and reviewing my journal notes, emotions, atmosphere, and researcher thoughts, the experiences were used to begin the findings section. To add depth to participant's poems I decided that there would be no 'he said' or 'she said' but words, phrases, and questions would be pulled from the transcripts to paint their journey and stories. Clandinin and Connelly (2000) expressed that weaving multiple accounts together produces a rich textured account of stories told. The researcher is positioned in the midst of both the process and outcomes.

### **Reflexive Engagement**

Focus on contexts of and relationships between researcher and participant shaped the creation of knowledge. Reflexivity is a dynamic process of interaction within and between ourselves and our participants, and the data that informs decisions, actions and interpretations at all stages. We are therefore operating on several different levels at the same time.

To be reflexive is to have an ongoing conversation about experiences while simultaneously living in the moment (Creswell, 2013). Reflexive research produces information on what is known as well as how it is known. It is not about just reporting facts or 'truths' but actively constructing interpretations of his or her experiences in the field, and then questions how those interpretations came about (Hertz, 1997).

As the researcher, I used a journal to document my own experiences, feelings, doubts, uncertainties, and reactions (Clandinin & Connelly, 2000, p. 86), in order to provide additional interpretations of the stories shared. Clandinin and Connelly (2000) shared that as these intimate relationships are shared when the researcher needs to come face-to-face with themselves throughout the process. This duality allowed for the inquirer to join the participants experience and the participants to become inquirers.

### **Tolerance of Ambiguity**

There is no exactness to the types of stories that will be heard. The storyteller begins from a point they are comfortable. The construction of their story is based on their reality. Each participant saw and interpreted the world to which they live in with Lyme disease differently and their stories were shared through their own experiences and personal belief system.

Narrative inquiry allowed us to hear how participants constructed their meaning from within their belief system (Clandinin & Connelly, 2000). We learned about attitudes, values, and ideas that shaped the sense of self for their identity. Clandinin and Murphy (2007) expressed that developed knowledge leads to minimal generalization and allows for wondering about the possibilities of imagining new norms.

As participants shared their stories I allowed for an organic and natural conversation to ensue. Participants were asked to start their stories from a point they were comfortable with and I respected their experiences by listening and asking appropriate follow up questions. These stories were personal, hard to share, and their own, not to be judged but to be respected. It was important that participants felt cared for and important; and they understood that their stories held meaning and value for the collective community of Lyme patients.

Meaning making occurred in collaborative co-constructed ways that provided the vision and deeper understanding of experiences. The series of interviews created a picture that captured vivid representations of experiences by asking questions such as, ‘what was that like?’, ‘do you have an image of that?’, ‘could you draw me a picture of that in words?’ (Clandinin & Connelly, 2000).

An epistemological stance, according to Leavy (2014), is a belief system about how research proceeds and how the researcher and participant’s relationships emerge. It helps everyone create their own reality through social interactions, relationships, and experiences. Levy (2013) shared that when our reality is constructed, there is a constant negotiation of meaning. Creswell (2013) stated that individuals seek understanding of the world in which they like to develop subjective meanings of their experience.

Creswell (2013) discussed that qualitative research is a set of interpretive practices that make the world visible. By utilizing a variety of sources, data can be collected within natural settings. This study collected data in the form of interviews, field notes, and document analysis. Once the data was collected the process of analysis began through transcription of interviews and a systematic review of the data. Using an excel spreadsheet I setup columns with the six dimensions of wellness identified and the rows were setup with the names being used for my participants. I would read the transcripts and would place words and phrases into the columns that made sense for the dimensions. Again, there was so much discussion about diets and financial issues that I added two columns to ensure the context of their experiences was being noted appropriately.

### **Researcher's Statement**

In full disclosure, I have a vested interest in this study, as I am a chronic Lyme patient. Creswell (2013) stated that in qualitative research “the study reflects the history, culture, and personal experiences of the researcher” (p. 54). My journey has been long and unpleasant, so I understand the struggles and the issues of the patients. I have my own thoughts related to healing and what keeps me going along this journey, but I am curious how others are experiencing and living with this disease. Creswell (2014) and Guba and Lincoln (1982) stated the importance of the researcher being open and transparent about the assumptions, beliefs, biases, and preconceived notions.

Even though I do not want my own story to overcome the participants', I value my participants knowing that I am linked to them through this experience. Hampshire, Iqbal, Blell, and Simpson (2014) indicated that as relationships move from researcher-informant towards one of friendship and mutual support, anxiety lessens, and shared stories of diagnosis, healing and treatment of Lyme disease continue to be experienced.

### **Assumptions**

The assumptions of this study were that everyone has obtained and works within different knowledge biases. By hearing multiple stories from different aspects related to the disease, a more robust and workable understanding was formed. This topic is controversial and sensitive, therefore, the stories that the participants shared related to diagnosis, treatments, and healing are protected.

### **Selection and Collection**

Participants from a self-identified group of persons with Lyme were identified and asked to join this study. The participants were required to be 18 years of age or older. Participants,

male or female, could be at any stage of the disease. This type of participant selection is known, according to Maxwell (2005), as purposeful sampling. These participants were contacted once my proposal was accepted and my Institutional Review Board amendment was submitted and approved. Once participants were secured they were asked to sign a consent form (Appendix B) and interviews were scheduled and held at a mutually agreed upon location. These semi-structured interviews were one hour in length and follow-up interviews were scheduled as needed for clarification. Because of the amount of time in the field and the level of in-depth conversations shared, a participant pool of eight people was selected. Sarris (1993) stated that since stories are not shared in chronological order deep relational connections must be cultivated.

For a year I have been attending a Lyme support group. During this time I have developed friendships with several people that also attended. One group session the facilitator asked me what had brought me to the group. I briefly shared my journey with Lyme but also told her that I was interested in researching the experiences of those with Lyme for my dissertation. She was excited and shocked. Excited that my topic had to do with Lyme and shocked that I am actually well enough to pursue a doctorate.

As the year progressed and stories, experiences, hopes, fears, and frustrations were shared, people began to show an interest in my study. In February, I was asked by the facilitator to sit on a panel for a support group session. The facilitator specifically asked that I share about my educational journey as a person with Lyme to show that even with challenges success and hopes could be realized. She also requested that I place a callout for participants to join the study. At the end of the panel discussion I had ten people that volunteered to participate. I collected their personal information and told them I would make contact once my study was approved. Phone calls began on March 19, 2018 and eight people agreed to participate.



The criteria for my participant selection was that of males and females, 18 years or older and had to have been diagnosed with chronic Lyme. As calls were made, I outlined the study and asked if they would be interested to participate. During this conversation it was understood that participation was voluntary and that they could withdraw from the study at any time. Additionally, they were informed that interviews would be set at a location that was close to them, the interviews would be recorded, and that their names would not be used only a pseudonym of their choice would be used.

Once the participants were confirmed, eight of ten agreed, one hour interviews were setup at mutually agreed upon locations close to the participant's areas of residency. Due to the nature of Lyme disease I was intentional about not inconveniencing the participants. Most interviews took place in private study room of libraries and a couple took place within participants homes. Prior to the interview beginning the participants and I talked through the design of the study again to ensure they were still willing to voluntarily share their stories. At the end of the conversation a consent form (Appendix B) was signed. The interviews proceeded with semi-structured and open ended questions for an hour, some lasting longer at the participants' request.

## **Data Collection**

### **Sampling**

I utilized purposeful sampling (Appendix C) techniques for participation selections. To support this sampling technique Creswell (2013) stated, "The concept of purposeful sampling is used in qualitative research" (p. 156). Contacts were made, via phone calls, to my personal network of people that self-identified with having Lyme disease and that meet the inclusion criteria. Bogdan and Biklen (2007) stated, "A good part of the work involves building a

relationship, getting to know each other, and putting the subject at ease” (p. 103), which happened during our group meeting. Leavy (2014) also said that “good rapport with participants may lead to richer, more honest, and higher quality qualitative data” (p. 429).

Creswell (2014) and Guba and Lincoln (1982) stated the importance of the researcher being open and transparent about the assumptions, beliefs, biases, and preconceived notions. Hampshire et al. (2014) indicated that as relationships move from researcher-informant towards one of friendship and mutual support, anxiety lessens, and shared stories of diagnosis, healing and treatment of Lyme disease will continue to be experienced.

### **Participant demographics and characteristics**

The information that follows will provide insight into the demographics and characteristics of the participants that agreed to participate in this study.

<b>Pseudonyms Name</b>	<b>Gender</b>	<b>Age</b>	<b>Number of years with symptoms</b>	<b>Number of years diagnosed</b>
Ellen	F	25	5 years	3 years
Jamie	F	48	18 years	12 years
Cassey	F	32	21 years	18 years
Ericka	F	27	20 years	1 year
Sindy	F	62	2 years	6 months
Leah	F	54	20 years	10 years
Kim	F	22	From birth	22 years
Peter	M	28	15 years	8 years

**Table 1**

I began the process with Ellen. She is a person that worked for the Department of Natural Resources (DNR) so she was familiar with Lyme disease from her training. She never dreamed that she would be one to contract Lyme disease. She has no memory of being bitten

and has no memory of any physical signs of the disease, but she does recall a time in the woods without Deet. Not sure if that was when she became infected, but something she frequently wonders about.

Jamie was exhausted and it was hard for her to share her story. She expressed a desire to help those around her that are being diagnosed, but she is at a complete loss with how to get those closest to her to understand what she is going through. She shares her library of Lyme books, as she reads all the time looking for a cure. She wants to be an advocate but does so mostly through social media as she does not get out of her house much. She has very little support at home from her husband and she is struggling to be positive and wonders why

The next was Cassey and she was feisty and ready for the world to hear her voice. She feels angry and frustrated most of the time when she cannot do the things she wants to do; but fear of what the future holds was what rang in her statements. She wants to be an advocate and desires to help people understand everything she had lived through.

I then met with Ericka she is divorced and feels like the changes that she faced physically and mentally is what led to the divorce. This is not uncommon in relationships. Anyway, she is now engaged and worries that the disease will be too much for her new finance to handle. They go to couples counseling and have a Lyme support group that they attend together to talk through issues and experiences in hopes of a life together.

Sindy was completely overwhelmed with everything she was learning about Lyme. She remembers going on a nature hike and seeing a sign that stated, "Ticks have been found in this area, please wear Deet." She did not pay attention to the sign and now wonders if this is when she became infected. She stated she was just thankful that her family was not with her and she is the only one suffering. Sindy asked if her husband could sit in on the interview because she did

not want to leave important details out and she felt having him there would allow him to fill in the blanks.

Leah was very matter-of-fact about the disease. She has done and continues to research the disease, to question medical professionals, and to ask questions of her insurance provider. She wants her story told, she wants people to ask questions, and she is adamant that Lyme disease needs to be a serious conversation had by all. She is very much an advocate, has tried many different types of treatments, and is starting a blog to track her story.

The next was Kim and she has had Lyme disease from birth and was born in Germany. She has experienced the psychological effects of Lyme disease. She has attempted suicide several times, has lost her child, and stays in dark secluded areas about 90 percent of her day because she does not want to hurt herself or others. Our interview was conducted in a dark study room in a library. She also had a companion with her so that if she had a flare up he would be able to escort her out of the library and home safely. This interview was heart wrenching and dark on many levels.

Finally I was honored to be able to interview Peter. He is a young man that is very strong in his faith and believes with everything in him the struggles that he faces daily will be used for the great good of this disease. He lost a full ride scholarship to medical school, knows he will never be a surgeon, yet has the most uplifting and positive outlook. At the time of writing this dissertation I am so happy to report that he just completed his first year of college. While it was a struggle for him, he is finding great confidence that his new goal of helping within the medical field can and will become a reality. He is and has the hope that we all need to get through this disease.

## **Semi-Structured Interviews**

From two pilot studies and a peer review process, semi-structured interview questions (Appendix D) were designed and successfully utilized. These questions continued to be utilized for the larger study. Leavy (2014) stated that semi-structured interviews make better use of knowledge-producing potentials and allow more leeway for following up. This was needed when trying to understand the experiences of the participants. When inquiring about a phenomenon the researcher seeks to find meaning and essence and Merriam (2002) recommended that interviews are preferred.

The self-identified people, that had already expressed an interest in this research study, received a phone call asking if they were still interested in participating and describing the study. Once confirmation of participation was received a time and location was set for the semi structured interview. The preferred location for this study was a private room within a public library close to the participants' area of residence, so as not to inconvenience or add stress to their lives. At the close of our time together the consent form was stored and locked within my home office filing cabinet. The recorded interviews were uploaded to my secure Box account. Once secure, the interview on my recording device was deleted.

## **Transcription**

During the pilot study interview, I transcribed the recording. From this process I learned a valuable lesson about research and myself. Research can be very emotional, touching, and both physically and mentally draining. Because the topic speaks to my own experiences, listening to the stories shared repeatedly brought on an emotional state that was almost too much to bear. From this lesson a statement was placed in the consent form to alert the participants that interviews would be sent to Rev.Com to be transcribed. While I understand that transcription is

a vital part of the process I felt that to produce the best outcomes I needed to step away from hearing the stories a second time. To re-engage with the interviews, I read and re-read the text, as well as reviewed field notes and observation journals while looking for connections.

### **Confidentiality of Data**

The information that was discussed during this study was, at times, painful to the participants therefore pseudonyms were utilized when the research was presented at conferences and for this dissertation. All documents were stored within the University's Box account and within a locked filing cabinet in my home office. Interviews were recorded and immediately sent to Rev.com for transcription. Once the transcriptions appeared in my university email account, and after the accuracy of the transcript was confirmed, all recorded documents were deleted.

### **Trustworthiness and Consistency**

Trustworthiness, also understood as validity, explained by Vagle (2014), is "sustained engagement with the phenomenon and the participants who have experienced the phenomenon" (p. 66). Therefore, making meaning of experiences could be discovered through continued conversation and reading and re-reading the transcriptions. To ensure consistency, I attended to clear and specific observational procedures. Clandinin and Connelly (2000) stated, "Just as a narrative inquirer has joined a field experience so too have field participants joined an inquiry" (p. 88). Experiencing feelings and thoughts that reflect the full essence of the participant provided an intrinsic system of meaning.

### **Data Analysis**

The data has been de-identified and the participants were asked to provide a pseudonym to replace their first name. All field notes, interview transcriptions, and other documents were

de-identified at the time of writing and are stored within a locked file cabinet within my home office. Additionally, all recordings are stored within a secure box account that Ball State provides for the students. Ethical considerations were ensured for this study by having prolonged engagement with research participants.

Stories can be viewed as socially situated knowledge constructions in their own right that values messiness, differences, depth and texture of experienced life (Polkinghorne, 1995). Gehart (2007) shared that analysis (meaning making) occurs throughout the research process rather than being a separate activity carried out after data collection. This is co-construction of meaning between the researcher and participant. As the researcher who asked for information, listened to the stories, and re-reading the transcripts, I took the data and compared it with my own personal understanding, without filling in any gaps. I combined the pieces of the stories to compose a poem to make sense of all voices together. Thereby, the process of data gathering and analysis became a synchronized harmonious and organic process.

As statements were organized and reviewed, a table was being created to show the demographics of the participants so that the data took on shape and meaning (Hatch, 2002). Additionally, exploration, description, interpretation, and situation of participants meaning making, was critical to an organized and transparent approach (Larkin & Thompson, 2012; Smith, Flower, & Larkin, 2009) of sharing their experiences.

The coding process was a critical link between data collection and the interpretation to make a meaningful story to share. From the open-ended interviews, I sorted the data through the six dimensions of wellness as my primary categories. This was the first set of inductive themes, with the awareness that other themes may also emerge. Groenewald (2004) emphasized that good research is not generated by data alone. This process was both natural

and deliberate – natural because emotions and feelings are captured, and deliberate because the goal was to find consistencies within the information shared.

All interviews were recorded and the recordings were transcribed by Rev.Com. Once transcriptions were complete, themes emerged, quotes from the participants were highlighted to potentially be used for the findings. Notes and reflections were analyzed and a sense of the culture of the experiences of healing and coping with Lyme disease was better understood through the lens of wellness.

Critically thinking through how best to state the findings from the data analyzed had become quite a challenge. The idea of just reporting “he said”, “she said” type quotes for each dimension of wellness does not tell a story. As I was reading the transcripts and continued to review the spreadsheet of words and phrases that I had identified for each dimension a conversation transpired between my husband and I. The topics of how best to display the content as well as what overall message needed to be presented were our constant conversation. We discussed, and I tried, side by side poems with context on one side and the dimension on the other, it didn’t flow. I tried combining everyone’s voice under one dimension and that felt cluttered and did not show the importance of the participants’ story. Then one night I looked at my husband and said, “What am I trying to show, why is all this important, and how do I show how much suffering is taking place?” He looked at me and said, “You just found your heading. You know they are out of balance and each person is unique.” Therefore, to present data collected and analyzed, a poem for each person and for each dimension of wellness was created. From the collective wisdom of the participants, I utilized direct quotes to form a collection of eight poems under one collective thought, suffering for



wisdom. The identified dimensions were used to provide a meaningful story that has depth, meaning, and impact.

Poetic criteria, according to Faulkner (2009), required the joining of areas such as understanding of human experience, reflexivity, and usefulness with empathy, social justice, and an understanding of writing poetry to make an expressive and inspiring flow of verses. Poetry returns the researcher back to the issue in order to demonstrate how theories arise out of experiences. Faulkner (2009) stated,

Meaning is made in that way, not found, and in its making it gets anchored in what appeals to the senses, the sensual, including bodies themselves . . . Science does not give us ordinary reality, the world we live in as we live it through our senses and our culturally programmed intellects (p. 25).

This process placed the focus of the reader on the issues and allowed the researcher to interpret voices to make meaning of the issue in a creative and collective manner.

### **Trustworthiness**

Trustworthiness was ensured for this study by having prolonged engagement with research participants, and this process continued throughout the entirety of the study. In order to establish credibility, I was able to build trust with the participants so they felt comfortable sharing their very real and personal stories of healing and coping with Lyme disease. These ongoing relationships continue to provide needed information to the Lyme community. While the whole story is still untold an attempt to cover as much of the culture of Lyme disease in a real and natural manner was realized (Fetterman, 1998).

The transferability of the information acquired was experienced through a form of inquiry that was essentially free of bias of any type of belief system (Lincoln & Guba, 1985). While I

too am a chronic Lyme disease patient, my story was not shared with the research participants during their interviews. The participants were asked to share their stories, from infection to diagnosis, with whatever detail they were comfortable providing, as well as being asked to answer additional semi-structured questions.

As I reflected on the process for the study with the lens of the researcher, I am reminded not only to place myself in the role of the participant, but to also walk alongside the participant to ensure understanding and perspectives. This practice allowed for meaningful data collection.

Information provided by participants can be verified, if needed, by requesting additional conversations. Also during the interview each participant voluntarily offered to provide additional documentation of their physician's notes, lab results, and treatment protocols if needed. While these documents were not asked for or received, the dependability and confirmability of their shared experiences is obtainable. Additionally, an audit trail of raw data, field notes, and transcriptions for each encounter has been kept for current reference and for later consideration and review (Lincoln & Guba, 1985). These materials have been stored in a secure Box location allowing myself access to all documents.

### **Chapter Summary**

The method utilized for this study was narrative inquiry to hear stories shared of the experiences of those that deal with Lyme disease on a daily basis. Creswell (2013) stated that the telling of stories through narrative inquiry can be done by way of poetry. Linking the stories through the creation of poetry provided an emotional and impactful written account of participants' lives. The research question was designed to allow participants to share their experiences and to try to make meaning of the stories heard. Data was collected from self-

identified people from relationships formed over a couple of years. The participants were interviewed and from the recorded interviews transcripts were created to analyze the data.

In order to share stories with meaning, feeling, and through their lenses and voices I decided to utilize poetry with a common theme, suffering for wellness, to show where people with Lyme disease are out of balance. Chapter 4 will reflect these stories shared by participants and will be displayed in poem form for each participant. Chapter 5 will draw the study together and discuss gaps and additional studies the might be completed.

## CHAPTER 4 – FINDINGS

*On most days I thrive on emotions, weave them into little stories, turn them into poetry and call it 'literature'.*

*-A. Reddy (Terrible Tiny Tales, 2017)*

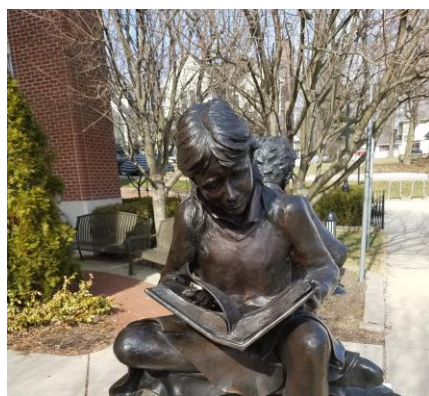
### Introduction

The day arrived, a new journey, uncomfortable yet exciting, all the while looking for people who understood Lyme disease, people who could help make sense of the disease and to help carry the burden. Through these people, we could recognize how our shared experiences connect and help us continue in the journey. The drive to meet the participants felt long, but it was just under two hours. The sun was shining; the air was warm; and there was a gentle breeze. It was a pleasant day for a drive. I worried only about staying awake for the journey, and wondered if the environment would be welcoming. I pulled into the library parking lot, only to have an anxiety attack, and it took twenty-five minutes of self-talk for the courage to open the car door. I was concerned about not knowing anyone and that the conversations shared would be very personal and sometimes painful. Was this the right choice? I was not sure that getting out of the car made sense and was praying for strength to carry on.

Was a support group necessary? Years of chasing medical symptoms only to be told that it is all in your head, or facing a medical situation that does not appear to have any definitive and prescribed treatment, forces people to seek answers, encouragement and support from others experiencing the same thing. A support group is an informal learning space that allows people to share issues and conditions that shapes the learner and influences their environments (Harrop & Turpin, 2013). All the while, it allows education to be passed along in many different formats

with supportive people that become friends. According to Roberts (2008) friendships are highly valued and an important part of the healing culture of a support group.

Seeking friendship and understanding, the action of opening the car door, ever so slowly, with movement toward the front door, was the first step. Oh! A statue! What does it say or mean? Anything for a distraction, but a gentle reminder, we must seek to learn.



**Figure 4:** Library Statue.

A community educator's role within an organization is to advance community knowledge and experience, provide diversity awareness, promote wellness, and encourage meaningful relationships (Caffarella & Daffron, 2013). According to Merriam and Brockett (2007), this type of education refers to any formal or informal action-oriented or problem-solving education taking place within the community.

People leading and participating in support groups, as stated by Henton et al. (2004), create networks that reengage citizens in their own communities and across communities in an effort to renew a universal understanding of a situation. Sharing knowledge, asking questions, and telling stories, all promote learning and develop meaningful relationships.

Enough delay, it's time to walk into the library to be greeted by a lime green, Lyme meeting sign. Well, here goes nothing! I was met by smiles and laughter. Were these people ill

or was this the wrong room? I signed in and was embraced by the leader to welcome me to a group where hope is the message. That's how the journey started and through this journey, I found people who were willing to help with this study. But more importantly, new friendships emerged.

### **The Group**

The group was started by people experiencing Lyme disease within their families. They connected first on social media by asking questions about treatments and diagnosis. The two co-founders began creating a network of Lyme carriers and relationships began to grow. Bloggers started sharing their stories and, by invitation only, the Facebook groups started to form and develop.

The co-founders of the group secured the use of two free library spaces in centralized locations for many of the people with whom they started connecting, Central and Southern Indiana (S. Coleman & L. Barta, personal communication, October 15, 2016). The co-founders then started working with people within the medical field to create a Board of Directors, a mission statement, a website, and informative pamphlets that they share between the two groups. From there, the group began to meet face-to-face two Saturday's a month.

L. Barta shared that the co-founders and Board of Directors met quarterly to ensure the groups were meeting both the mission and vision for the group (personal communication, October 15, 2016). They established programs to be shared at both meeting locations, thus providing everyone ample opportunity to attend either meeting to hear the same message. According to S. Coleman (personal communication, October 15, 2017), in a normal year, there are five formal programs planned, two months that they do not meet, and five informal meetings where participants share their stories of hope and help each other through issues they are facing.

Additionally, because Lyme is not universally recognized as a chronic disease (Horowitz, 2013), the co-founders started offering professional development courses to medical professionals who want to learn more about the experiences of the support group participants. This is a new venture. The training materials are being co-created by a well-known medical professional in Washington, D.C. that treats Lyme patients, the co-founders, and a select group of group participants. Harrop and Turpin (2013) share that working alongside each other provides co-support and everyone learns.

There are so many areas of concern, treatments, questions, and myths that people with Lyme disease need to be educated about options and ways to learn from and talk with others going through the same thing. Some people would ask, are there a lot of people that suffer from Lyme disease? Since this is not classified as a chronic illness (Horowitz, 2013), is it really an important venture? To those that do not have knowledge of the disease or of the physical, emotional, medical, and mental issues that Lyme carriers suffer (Horowitz, 2013), these would be valid questions. For those suffering with Lyme, the critical and incurable medical issues that arise (Horowitz, 2013) provide a need for a space and opportunity to talk to others who are experiencing the same issues. The Lyme support groups provide such a space.

### **Participants**

During group sessions, I acted as a participant observer and attended the meetings primarily for my own personal needs, not solely for preparing the research study. However, through these and other group sessions, I was able to identify eight participants willing to interview with me for this study. These participants self-identified as being willing to participate in the study after one of our support group meetings. The eight participants agreed to a one hour interview to share their Lyme experiences.

**Ellen.** I met Ellen in a private study room at a library in central Indiana. She was in visible pain and struggled with light sensitivity during our interview. Even though I asked to reschedule for her convenience, she wanted to complete the interview, albeit in the dark.

**Jamie.** I met Jamie in a diner in Southern Indiana. Over lunch, she openly and boldly shared her journey with Lyme. She was laughing, crying, and staying hopeful throughout the telling of her story.

**Cassey.** I met with Cassey in a private study room in a library in central Indiana. Feisty and ready to change the world with her story. Cassey has a desire to be an advocate for those with Lyme and hopes the information collected will bring about change.

**Ericka.** I met with Ericka in a private study room in a library in Northern Indiana. Ericka who was recently diagnosed with Lyme, after years of illness, was very confident about the story she wanted to share. Mid-twenties, angry, and frustrated, Ericka shared her story with tears and concern.

**Sindy.** I met with Sindy in her home on a lake in Northern Indiana. A retired active grandmother, Sindy was afraid that she would not be able to answer my questions fully and asked for her husband to be able to join in our interview. While upbeat and willing to share, Sindy wanted to be sure that her story was correctly articulated.

**Leah.** I met with Leah in a quiet restaurant in central Indiana. She is in her mid-fifties and speaks in a strong and matter-of-fact manner about her journey. She wants her voice to be heard and is very much an advocate for those families dealing with Lyme disease.

**Kim.** I met with Kim in a private study room in a library in central Indiana. While struggling with the disease, she told her story through an indignant manner. The heart wrenching story shared left me in tears and very unsteady.



**Peter.** I met with Peter in his home in central Indiana. Sitting in the sunroom watching an intelligent young man struggling to find the words to share his story, as his service dog sits close by. He has a smile on his face and through the whole interview states multiple times and in different ways that God has a plan for his life through this struggle.

### **Suffering For Wisdom, Out of Balance**

According to Merriam-Webster Dictionary, (2018), suffering is the state or experience of loss, damage, pain, or distress. Nhat Hanh (2017), a Buddhist monk and scholar, shared that part of acknowledging suffering is also acknowledging that we need help. A community, such as a support group, helps us to not lose hope. Nhat Hanh (2017) wrote that when we have compassion in our heart, we suffer less because compassion has the power to heal. By taking refuge in the community, known as the support group, and through sharing wisdom, we will be able to help others as well as self. One process for accepting suffering includes stating three sentences that can help when you are angry or as we are searching for wisdom.

I know I'm suffering;

I know that you are suffering too;

I need your help. (Nhat Hanh, 2017, p. 76-77)

These simple phrases remind us that we can offer to be a refuge for each other, rather than making things worse.

The stories shared during the interview process all expressed suffering. Suffering that made their worlds unbalanced in one or more areas; and every participant was searching for wisdom. While the voices were different, the stories were very much the same. In order to share the findings as a collective voice, poetry will be used. Faulkner (2009) shared that poetry for social researchers should motivate or touch the readers. After researching different types of

poetry, it was decided to create a free verse narrative poem for each participant. The idea was to show the suffering of those with Lyme and to show the areas that are out of balance. Through the six dimensions of wellness, we hear their imbalances and better understand the struggles for people with Lyme disease. Faulkner (2009) expressed that poetry allows the researcher to enter into an experience as self, observing and recording, but the researcher does not presume to speak for the participant.

### **Poetry Derived From Interviews**

Faulkner (2009) shared that poetic work should expand perception, inspire dialogue, and develop conversation by hearing the voice of the participants and feeling their emotions. To make this happen poems were setup to tell stories. The poems start with the very place that ticks live, are followed by compelling expressions of life, and end with a story of hope and encouragement.

The poems you are about to read share the stories of pain, suffering, and at times hope that Lyme patients shared. Charon (2006) stated that when joining narrative methods with processes, like poetry, we can improve healthcare, patient advocacy groups, health activist organizations, international health bodies, and public health organization while conceptualizing the process of health care in wider frames. By using poetic criteria the impact of the stories show more truth and discovery.

#### **Ellen**

Ten years of symptoms, misdiagnosed along the way  
 Fibromyalgia, thyroid issues, multiple sclerosis, and anxiety  
 Rocky Mountain spotted fever, memory loss, and blood clots  
 Suffering for wisdom, out of balance physically

Multiple trips to the emergency room, bones aching so bad I cry

Neurological symptoms and no strength in my limbs

ELISA and Western Blot to discover the cause

Suffering for wisdom.

Working at a State Park, out in the woods

Knowing that DEET fends off nature

Lab work at Lilly and mycoplasmas, exposed

My career grows, only to lose it all

Suffering for wisdom, out of balance occupationally

Stay at home mom, not what I expected

Trouble taking care of the kids needs on a daily basis

Feeling of uselessness and only a shell of the person I once was

Suffering for wisdom.

Try to be social, PTA and Zumba

Only to end up in the dark and alone

Canceling play dates, appointments, and meals

Suffering for wisdom, out of balance socially

Afraid and alone, no one understands

Cannot carry on a conversation, very little word recall

Seclusion with no energy, I just cannot go

Suffering for wisdom.

Researching symptoms knowing there is something wrong

Google, WebMD, Wikipedia, books, and people

Facebook groups, videos, and conversations with multiple medical doctors

Suffering for wisdom, out of balance intellectually

Lesions and rashes, linked to Lyme disease

False negative blood tests, twenty-nine vials each time

Suffering for wisdom.

Holistic what does that even mean?

Ten drops of lavender, meditation, and crystals

Suffering for wisdom, out of balance spiritually

Good moral compass, is that what it takes

Science and religious balance, not today

Suffering for wisdom.

How do I get to my normal state?

Relief, anger, confusion, and education

Suffering for wisdom, out of balance emotionally

Depression, anxiety, chronic, and ill

Crying outbursts, good days and hope

Suffering for wisdom.

Hundreds of dollars that I do not have

Needing insurance help that does not exist

Suffering for wisdom, out of balance financially

Purchasing meds only when I can

Missing critical doses when I can't

Suffering for wisdom.

Food is an issue, watch what you eat

High fat, low carbs, and protein

Keto is the process for me

Suffering for wisdom, out of balance dietetically

Suffering for wisdom.

### **Jamie**

Bullseye rash, declining health, PICC line, septic, and surgeries

Falling down, vertigo, loss of weight

Suffering for wisdom, out of balance physically

High fevers, blood pressure issues

Stroke, epilepsy, and narcolepsy

Suffering for wisdom.

Working with human resources, to maintain employment

Able to teach, but limited schedule

Suffering for wisdom, out of balance occupationally

Disease breaking the brain barrier, cannot remember the steps

Other instructors coming to my aid

Suffering for wisdom.

People do not believe, it's just Lyme, take an antibiotic

Lost license, no car, no memory, and meds too strong

Suffering for wisdom, out of balance socially

Husband transports me to work every day

Cancelling social events, alone and afraid

Suffering for wisdom.

Lyme does crazy things to all it touches

Solutions and meds: pills, drops, and CBD oil, does not make sense

Suffering for wisdom, out of balance intellectually

Columbia Med, Google, and books

Research continues, there has to be a solution

Suffering for wisdom.

Faith, prayer, hope, and promises

I cannot do this alone, God are you there?

Suffering for wisdom, out of balance spiritually

I just want to quit and I really do not care

Down on my knees once again

Suffering for wisdom.

No modern family, no kids unless adoption

Frustration, concern, and confusion

Suffering for wisdom, out of balance emotionally

Lost so much, future is uncertain

Gives new meaning to 'in sickness and health', will he stay

Suffering for wisdom.

Cash payments needed, \$1,500 a month

Insurance denial, no matter what is prescribed

Suffering for wisdom, out of balance financially

Increasing debt, second mortgage, bankruptcy to live

Suffering for wisdom.

Food is an issue, watch what you eat

High protein, low fat, low carbs

Whole 30 is the process for me

Suffering for wisdom, out of balance dietetically

Suffering for wisdom.

### **Cassey**

Unexplained surgeries, carpal tunnel, and Achilles

Iron, anti-depressants, and many vials of blood

Suffering for wisdom, out of balance physically

Alzheimer's, ADHD, hormonal treatments

A breakthrough from overseas, Ozone to help me function

Suffering for wisdom.

Always a mother and housewife, no outside job

Normal daily chores a struggle

Naps just to make it through the day

Suffering for wisdom, out of balance occupationally

Breakfast, lunches, and dinners to fix

Homework to help with, cannot think straight

Suffering for wisdom.

Profound exhaustion makes socializing non-existent

No meals out because diet has changed

Suffering for wisdom, out of balance socially

Social media to communicate

Not out of pajamas, no combing the hair

Circle of friends with understanding shrinking

Suffering for wisdom.

I am not out of my mind, but I do blame myself

Ticks don't stop at state lines and I know that

Suffering for wisdom, out of balance intellectually

Lyme literate doctors are extremely hard to find

Education on Lyme is needed for all

Suffering for wisdom.

Faith, hope, not sure I believe

Too many unexplained with no answers

Suffering for wisdom, out of balance spiritually

Trust, trust of who, being vocal of the injustice

Needing a counselor to cope

Suffering for wisdom.

Husband supportive, but had to convenience him

Glad to have thirty years together, before chaos

Still marriage counseling to get through

Suffering for wisdom, out of balance emotionally

Lyme ruins your life, steals from you

Anger, frustration, pain, and complete change

Suffering for wisdom.



No prescriptions under insurance pay

Appointments not covered either

Supplements, seventy-four or more, all paid out of pocket

Suffering for wisdom, out of balance financially

\$2,500 herbs, IV's are more, Ozone it's cheaper to purchase the chamber

Still no assistance, savings and retirement gone

Suffering for wisdom.

Food is an issue, well this is new

No sugar, lots of vegetables and fish

No set diet, but I watch what I eat

Suffering for wisdom, out of balance dietetically

Suffering for wisdom.

### **Ericka**

Mono, Postural Orthostatic Tachycardia Syndrome (POTS),

Cardiologists, Rheumatologist, Endocrinologist

Suffering for wisdom, out of balance physically

iGenex, nausea, probiotics

Epstein - Barr virus, mycoplasma, brain fog

Suffering for wisdom.

Afraid for my job, missing too many days of work

Change career paths, something easier

from Master's level back to entry level

Suffering for wisdom, out of balance occupationally

Feeling so stupid for tasks cannot complete

The boss thinking poor work ethic, need to replace

Suffering for wisdom.

Divorce, dating, engaged to be married

So many changes, fiancé having doubts

Suffering for wisdom, out of balance socially

Cancelling on friends, they do not understand

Not looking ill, but not able to participate

Suffering for wisdom.

Lyme book by book, Web MD

Research and articles, discovered a silent killer

Suffering for wisdom, out of balance intellectually

Bloggers, websites, social media posts

Which treatments and care work, nobody knows

Suffering for wisdom.

Not spiritual, no faith, no hope

A good God would not allow something this awful to happen

Suffering for wisdom, out of balance spiritually

Rethink, need to lean into something bigger than a disease

This disease has pushed me to seek

Suffering for wisdom.

The ups and downs, the good days and bad

Hibernating away from people and events

Suffering for wisdom, out of balance emotionally

Irritable, mood swings, anger, and fear

Frustration and confusion, not sure what to expect

Suffering for wisdom.

Cannot afford treatment, bankruptcy is next

Fight with insurance with no end in sight

Suffering for wisdom, out of balance financially

Suffering for wisdom.

Food is an issue that I cannot juggle

No sugar, nothing white, lots of vegetables, yuck

No set diet, but I watch what I eat and still gain weight

Suffering for wisdom, out of balance dietetically

Suffering for wisdom.

### **Sindy**

No control of body, tingles in my limbs

Rapid heart rates, heart attack or stroke

Suffering for wisdom, out of balance physically

Stress, dehydration, blood in urine

Cannot speak and a spinal tap

Suffering for wisdom.

Retired grandmother, living on an active lake

Cannot be alone with grandchildren

Cannot be on the lake

Suffering for wisdom, out of balance occupationally

Suffering for wisdom.

Family events cancelled, or found asleep on the couch

Pool parties, hiking, stay behind or inside, cannot participate

Suffering for wisdom, out of balance socially

Invitations declined, no social events

Friends trying to be understanding, but feeling neglected

Suffering for wisdom.

Tick warning signs, we live in the woods so no worries

Should have dressed appropriately and with bug spray

Suffering for wisdom, out of balance intellectually

Be your own advocate, no one can speak for you

No additional income, retired, won't drain my savings

Suffering for wisdom.

Always somebody worse, strong faith needed

Asking for prayers and leaning on my Creator

Suffering for wisdom, out of balance spiritually

Mediation and oils, not sure this helps

Trying to stay faith filled, but questioning the process

Suffering for wisdom.

No way to describe the emotional mess

Desperation, uncertainty, intrusive and painful

Fear is the overarching consent

Suffering for wisdom, out of balance emotionally

Suffering for wisdom.

Cannot keep up with putting money into treatment

No insurance, no income, and no way to change it

Suffering for wisdom, out of balance financially

Suffering for wisdom.

No gluten, no sugar, no dairy, nothing white

Fish and chicken, a lot of the time

Vegetables and fruit, clean eating for me

Suffering for wisdom, out of balance dietetically

Suffering for wisdom.

## **Leah**

Joint pain, muscle reduction, TB, Syphilis

Blurred vision, trouble walking, brain tumor

Suffering for wisdom, out of balance physically

Parkinson's, Muscular Dystrophy, cannot hold up my head

All the symptoms, but it's not, but what?

Suffering for wisdom.

Working in business, sick days abundant

In lost time, no flexibility for time off, no more job

Suffering for wisdom, out of balance occupationally

Cannot get hired, no thought process to interview

School an option, cannot focus to read or write

Cannot remember how to study, dropped out

Suffering for wisdom.

Need a network to assist with medicines, appointments, and driving

Cannot leave home, where do I find help

Suffering for wisdom, out of balance socially

Chat on social media, but will not go out

Too hard to communicate, no energy to try

Suffering for wisdom.

Just need to exercise more, but I cannot stand

Suicidal thoughts frequently, I do not understand

Suffering for wisdom, out of balance intellectually

Learning through research and listening to explanations

Struggle with what is presented

Need infectious disease doctor, but where to find one

Suffering for wisdom.

Prayer a daily need, for healing and understanding

Believe chosen for this journey, but not sure why

Suffering for wisdom, out of balance spiritually

Faith to endure, scripture to support

Suffering for wisdom.

Friction within home life; scared and uncertain

Outbursts and sleeping, for no reason

Suffering for wisdom, out of balance emotionally

Irritated and exasperated, mood swings and tears

Never really sure how to feel, or who will appear

Suffering for wisdom.

Too much money spent for treatment

Going to be in bankruptcy soon

Suffering for wisdom, out of balance financially

Retirement dwindling, nothing to spare

Suffering for wisdom.

Gut health, grain free, and anti-inflammatory

Learning foods to heal

Suffering for wisdom, out of balance dietetically

Suffering for wisdom.

## **Kim**

Depression and panic attacks to things much worse

Asperger's syndrome and ovarian cysts

Suffering for wisdom, out of balance physically

Pre-schizoid and narcissistic personality disorder

Suffering for wisdom.

My job, was a mom, got sick and had to give my baby up

Working part-time, could not hold a job

Suffering for wisdom, out of balance occupationally

Suffering for wisdom.

Isolated myself to cover it up

Not many friends, don't want to burden others

Suffering for wisdom, out of balance socially

Suffering for wisdom.

Need a specialist, none to be found

Do not know who I am without Lyme, born with it

Suffering for wisdom, out of balance intellectually

Suffering for wisdom.

No way there is anything spiritual to discuss

No higher power would allow suffering like this

Suffering for wisdom, out of balance spiritually

Suffering for wisdom.

Overwhelmed and numb

Believe I will die young

Suffering for wisdom, out of balance emotionally

Suffering for wisdom.

Money, none in my pocket, cannot get treatment

Insurance works with billing codes, Lyme is not available

Suffering for wisdom, out of balance financially

Suffering for wisdom.

Eating disorder, avoidant and restrictive food intake

No sugar, no grain, no dairy, and nothing that is not clean

Suffering for wisdom, out of balance dietetically

Suffering for wisdom.



**Peter**

Active outdoorsman, hiking, camping, and sports

Then, for no reason, injuries galore

Attacks on immune system, whooping cough, pneumonia, and strep

Paralysis, face drooping, wheelchair bound

Neck brace, service dog, no longer self-sufficient

Suffering for wisdom, out of balance physically

Ataxia, Parkinson's, lost vision and voice

Numbness, seizures, night terrors once more

Suffering for wisdom.

Part-time work as a high schooler, into college we go

Full ride scholarship to Medical school

The goal orthopedic surgeon

Suffering for wisdom, out of balance occupationally

Fired due to memory loss and physical restrictions

Woke up to a new life, paralyzed and afraid

Med school to 3<sup>rd</sup> grade reading level, with no warning

The disease broke my brain barrier

Suffering for wisdom.

New life, no friends, isolation

Sensory overload; lights off, blinds down, no sound

Suffering for wisdom, out of balance socially

Close friends, no more, no one understands

No way to communicate, no way to get out  
Suffering for wisdom.  
Research of symptoms, many styles and many hours  
Watching family and friends suffer along  
Suffering for wisdom, out of balance intellectually  
Loss of dreams and cannot dream of new  
I know I'm smart, what is wrong and why  
Suffering for wisdom.  
God leads and God works  
God won't waste suffering, but when?  
Suffering for wisdom, out of balance spiritually  
Meditate day and night so that God can work  
Petition with thanksgiving, present requests to God  
Joshua and Philippians the Bibles words etched in my mind  
Suffering for wisdom.  
Tears and frustration; determination yet hope  
Happy for progress; hoping healing comes fast  
Suffering for wisdom, out of balance emotionally  
With God I will make it through everything  
Belief, truth, or myth, your choice  
Suffering for wisdom.  
No income, relying on parents  
Mortgaged home three times over

Friends and church family pitching in when they can

Suffering for wisdom, out of balance financially

Suffering for wisdom.

Feeding through tubes for so many years

No more junk food, sugar, or grain

Suffering for wisdom, out of balance dietetically

Clean eating, sounds gross, does not taste any better

Vitamin and medical cocktails, protein, and vegetables

Suffering for wisdom.

### **Thoughts About Interviews**

In conclusion of these interviews, the stories, heart wrenching and real, left me grateful to not be alone, but wondering why. Why so many people have to suffer through this disease alone and out of balance. Dr. Horowitz (2013) stated that while people experience different symptoms the disease is the same. Suffering with Lyme disease is a constant struggle and takes time and patience to arrive to a road of healing. Dr. Horowitz (2013) wrote that people with Lyme disease should grant themselves the gift of time and patience because restoring health takes work and perseverance.

Feeling, hearing, and seeing the struggles through our conversations left me wondering if medical professionals who treat Lyme disease would say the same things about the disease. Clandinin and Connelly (2000) stated that researchers while in the field hear stories as they are told yet still wonder about the basis of the story. This leads me to continue to engage in narrative inquiry by seeking other experts on the topic to determine fact or fiction being shared. The

process to determine fact or fiction is then lead by more questions to have answered, more reflection to be done, and more conversations to be held. This process sparked a need to be able to provide meaning through additional trustworthiness.

The additional trustworthiness was designed to provide a certain respect and power to the stories that were shared. The voices of the participants are their truths and since they already feel like no one listens or acknowledges that what they are saying is real, it became important to me to ensure every reader comes away with a feeling that a full and accurate picture was provided. To provide support to the participants' truths, I decided to reach out to two Lyme medical providers to see if they would be interested in providing their thoughts and experiences regarding Lyme disease.

### **Medical Aspect**

The stories shared are powerful and many times they just do not seem real. As I sat in the circle of the support group and listened to the struggles, hopes, and fears, it occurred to me that one of the major questions asked was, which medical professional do you use? Several people started with general practitioners and, after learning they were not Lyme literate, then started searching for anyone that could 'talk Lyme'. Four names of medical professionals were frequently mentioned. As I listened to the stories about the four Lyme doctors from the participants, I wondered if the doctors would talk to me. I hoped they would provide me another perspective of Lyme disease or just confirm the crazy life of 'Lymies'. Could I ask them to share their experiences with Lyme? While it occurred to me that this is another research study, it was at least worth a conversation to see what might be discovered to confirm or support this study.

Two names appeared within my field notes multiple times. One of the medical professionals I know well and the other I had heard great things about, and if money were no object I would be going to them. So I reached out to their medical assistants to ask if they would be willing to talk about the life of people with Lyme. To my surprise, each agreed to talk with me, one for an hour and the other for thirty minutes. While I know the stories are real, I immediately felt affirmed and supported in my research study with these confirmations.

As both of these medical professional work outside of the formal boundaries of the medical profession, they are under legal attack from insurance companies, the CDC, and others. One medical professional asked that I use his name and the other asked that I use a pseudonym. Out of respect for them, I honored their requests. Both of the medical professionals began their careers focused on areas that were not related to Lyme disease. When the disease became personal to their families or a consistent theme with their patients, they changed their focus to serve those with Lyme disease.

### **Dr. Jemsek**

For twenty-three years, Dr. Jemsek treated patients with HIV/AIDS, and he thought that would be his life's work (personal communication, May 15, 2018). However, in 2000, the bacteria Borrelia continued to appear in his patients, and by 2006, he shifted his focus from HIV/AIDS to Lyme. When his first clinic was forced to close, he opened another clinic on the east coast only treating Lyme patients.

Dr. Jemsek is a leading researcher and a pioneer in the development of treatments for Lyme. Dr. Jemsek stated most of his HIV patients used to die, now most live with chronic illness (Diener, 2017). The Lyme patients he sees now are really sick, want to die, but they cannot. Suicide is the most common cause of death in Lyme disease,

according to Jemsek (personal communication, May 15, 2018). People that suffer with Lyme Borreliosis, in the chronic state, have an inferior quality of life, even compared to those with HIV/AIDS (Diener, 2017). Dr. Jemsek is quoted as saying:

When patients come to see us, the sick folks have usually been seen by up to ten to twenty doctors and often have been referred to major medical centers, ranging from Mayo to Cleveland Clinic, Duke, and others. They have had numerous tests, trials of therapy, and are often left with labels such as depression, fibromyalgia, chronic fatigue, MS, and more. They're not happy because they've spent up to or exceeding \$150,000 and they are suffering and/or dysfunctional (Diener, 2017, p. 57).

Dr. Jemsek (personal communication, May, 15, 2018) shared that he has cared for a lot of very sick people with complex symptoms. These people had been to countless medical professionals and were told that their stories and symptoms were fabricated nonsense. As a medical professional, he believes that "if you listen to your patients they will tell you what is wrong, and we are required to help them" (personal communication, May 15, 2018). Dr. Jemsek stated that he got into medicine "to heal and when given the gift of healing you better use it" (personal communication, May 15, 2018).

Dr. Jemsek explained that Lyme disease is a tick-transmitted infection caused by the spirochete *Borrelia burgdorferi*. Spirochetes are top of the food chain. They look and move like corkscrews, and they inflict misery on anyone with them. Because Lyme autoimmune disease transmits within the blood stream, it can be sexually transmitted, is hard to kill because it hides within bones, tissues, and muscles, and it creates abundant

and deeply embedded infections within patient's systems. It can look like many different types of common ailments, and it is deadly (personal communication, May 15, 2018).

Dr. Jemsek also shared that those with Lyme disease face desperately bleak outcomes financially, occupationally, emotionally, and physically. The disease affects our economy, and people are forced to go on welfare and disability. There is no quick cure, multiple prescriptions and herbals have to be used and pulsed in order to start killing the infections, and there is no guarantee that the treatment chosen will work. "People with Lyme disease need a miracle" (Dr. Jemsek, personal communication, May 15, 2018).

#### **Dr. Len**

Dr. Len worked for a hospital in central Indiana when his wife and young son both contracted Lyme. Feeling hopeless and looking for answers to help his family, he studied Lyme with Dr. Jemsek, and then opened his practice in Indiana.

Dr. Len shared stories that were very similar in nature. He shared that his patients experience some relief in warm climates, but there is no scientific evidence as to why there is a sense of feeling better (personal communication, June 1, 2018). Dr. Len stated:

It is complicated to be a physician that treats Lyme. There was not training in medical school for this disease. We pursue testing and many different types of treatments to try to assist patients with the pain and dysfunction that they experience. It is a lengthy and costly process for patients and physicians alike. I pursued this career to make a difference and yes, there are days I get as frustrated, depressed, and as confused as my patients, but I won't stop until we have answers.

Because our conversation was short I was not able to glean very much information. Dr. Len agreed that Lyme patience's go through horrible struggles trying to get a diagnosis, and there are so many aspects of their lives that have to change that there is

No way they have peace, balance, and at times hope within their lives. I have first-hand experience as I have seen it, lived through it, and still battle it within my family daily. I give my patients credit for trying to have a normal life through this horrible chaos. (Dr. Len, personal communication, June 1, 2018).

To conclude, both of these medical professionals have stopped practicing within their learned medical field in order to research this disease. They have left secure employment to open private clinics. They have experienced the symptoms that the study participants have shared, in some form or other, and they are regularly being sued with the threat of losing their license. These accounts provide trustworthiness and another source of affirmation to the participant stories.

### **Chapter Summary**

As I reflect on my experiences with each participant, it occurred to me that while the stories had many similarities, the feelings that ensued while listening were different for each. The participants and I shared laughter, tears, hopes, and fears. It is hard to believe and understand that one disease can create so much havoc, and I am honored to have heard stories from both participants and medical professionals.

The words used for the creation of the poetry shared were pulled from the interview data directly obtained from each participant. Their experiences were presented through the writing of poetry so that the reader would be able to feel the pain, fear, anger and hope expressed.



The poetry that was presented relates to literature reviewed. Literature shows that Lyme is hard to diagnosis, hard to treat, and changes the lives of those that are infected and not treated quickly. Therefore, participants voices have been heard through poetry, medical professionals' voices were heard to provide trustworthiness and support for the participants, and literature shares these issues and others where Lyme disease is concerned.

## **CHAPTER 5 – DISCUSSION**

*I believe that illness has led me to a life of gratitude, so I consider Lyme disease, at this time in my life, to be a blessing in disguise.*

*-R. Wells, Lyme Survivor (Faith, 2017)*

### **Introduction**

Lyme disease is complicated to live with. It changes lives in ways that no one can predict or imagine until living through it. Lyme disease provides an imbalance to life not only within the six dimension of wellness, but financially and dietetically as well. The previous chapter presented these findings in the form of poetry taken directly from the interviews with the participants.

This chapter discusses the findings and allows for researcher reflections to be noted, research conclusions, implications to be presented, and finally, provides recommendations for future studies. The chapter concludes with a summary of the research.

### **Discussion of the Findings**

While the stories shared were very personal and at times very painful, the experiences were very similar. The study achieved the limitations of saturation rather quickly. This means that while each participant had somewhat different experiences of where and how they contracted Lyme disease, their struggles, symptoms, and lack of accurate and timely diagnosis was not experienced. Additionally, the stories started sounding and feeling very much the same and the six dimensions of wellness were observed through every story. In addition to the six dimensions, occupation, physical, social, intellectual, spiritual, and emotional, two additional themes of imbalance were identified as financial and dietetic.

The cadence of the information shared is one of fear, frustration, and confusion. The medical field is advanced in so many ways, but there appears to be little help provided to those with Lyme disease. The participants lived in different parts of Indiana. They all were different ages, and had different backgrounds, yet they are a community seeking answers and hope.

The study was designed as a narrative inquiry. Clandinin and Connelly (2000) stated that people identify with stories through listening to accounts from others and then recording and sharing the stories in a meaningful way. Charon (2006) shared that bearing witness to the suffering of each other creates community, as was experienced through this study. In order to represent the interviews, a poem was created for each participant, so their emotions and struggles could be identified and felt by the reader. Faulkner (2009) argues that researchers can use poetic representation as a means to evoke emotional responses in readers to produce shared experience and understanding.

The study was designed by asking the research question of “How do the participants narrate stories about their experience living with Lyme disease?” The participants answered this question in great detail as they recounted their journeys and allowed a glimpse into their lives. They shared how their lives felt out of balance and how they coped with the daily challenges. The new normal of being out of balance and suffering was expressed by every participant.

### **Recognizing the Six Dimensions of Wellness in Lyme Patients**

As a reminder, Adams et al. (2000) shared the definitions of the dimensions of wellness:

- Occupational is the perception that one will experience positive outcome through events and circumstances within their work life.

- Physical is the perception and outcomes of physical health.
- Social is the perception of having support from family or friends.
- Intellectual acknowledges the perception of optimal learning through stimulating activity.
- Spiritual possess a sense of the meaning and purpose of life.
- Emotional is a secure self-identified positive sense of state of mind.

Reflecting on the meanings and stories that were shared regarding the dimensions of wellness, it was evident that those with chronic illness face daily challenges in multiple areas of their lives. Charon (2006) expressed that illness forces one to question how to live, how to trust, how much life means to you, and how much suffering one can bear.

After reviewing the findings, it was appropriate to add the dimensions of financial and dietetic wellness. McFadzean (2010, 2012) defined these dimensions in his later writing. Financial wellness is the perception that money is no issue. Yet, the financial implications go beyond loss of money, it is also the loss of employment and loss of assets. “The multiple costs of the illness . . . am I going to lose everything over this” (McFadzean, 2012, p. 210)?

The dietetic wellness definition is perceived as a strict and prescribed dietary and nutritional program. According to McFadzean (2010), becoming conscious of one’s diet plays a vital role in offsetting the effects of antibiotics, bolstering the immune system, aiding detoxification, decreasing inflammation, healing the gut, and preventing candida overgrowth. Changing one’s diet is a big part of living with Lyme as a chronic illness.

As each participant shared their story and experiences the six dimensions of wellness, while not directly stated, was clearly part of their journey. Job loss or fear of and actual job

changes were experienced. All had physical limitations that they were learning to work within, emotional struggles were experienced within self and with family members, and social limitations and lack of participation within activities were realized with life adjustments being made. Also, each participant knew they needed to research and become versed on symptoms and treatment options. All this while trying to decide how their spiritual wellbeing was affected, or if it was. These likenesses expressed the balance that was missing for each.

If being out of balance with the six dimensions was not enough, participants also shared issues with food consumption and financial exhaustion. Adding these two dimensions expresses how the whole body of a Lyme patient is affected by this disease. McFadzean (2012) stated that Lyme disease and infections unbalances the immune system and everyone with Lyme will have to treat from the inside out to regain balance within every aspect of their lives.

It was implied and at times expressed that coping with Lyme disease forces one to look at the world around them in a different manner. Buhner (2013) expressed that plants or other vegetation could be a help tool instead of just a pretty flower. This means that there will be a time that some treatments work and others do not. Horowitz (2013) shared that coping is not worrying about protocols that work for others, but learning to live with the protocols that are being designed for you.

The inference during the interviews was that people with Lyme go through many stages of coping. Stages of anger that they have the disease, acceptance of life changes without full understanding, exasperation that treatments are not working and at times a poor me mentality. Then, and most times with no warning, the coping transitions to learning to live with the disease, accepting that changes have to take place in their daily lives, and then deciding to make the best

of what is happening with a countenance of how can I help self and others. Diener (2017) identified coping the best, by saying,

Since I know there is no “cure” for Lyme disease, especially for a person who has been infected as long as me, I will need to find my new normal and live into it. I pray that I will never regress and need to return to a treatment protocol, but if I do, I know the doctor who will help me face it and find health again.

To cope according to Merriam-Webster Dictionary (2018) is to deal with and to attempt to overcome problems and difficulties. Each of the participants shared this process and while some handled coping through a spiritual sense others are still angry and searching, but no matter where they are in the process, they are coping the best they can with this life changing disease.

### **Community Education and Lyme Disease Support Groups**

Lyme disease is one of the fastest growing medical issues in the world (Gifford, 2016). According to the Lyme Disease Association (LDA, n.d.), Lyme is active in 80 plus countries worldwide and studies show that areas suitable for tick habitation will increase by 213% by the 2080's. Everyone needs to be educated about this disease and people with the disease need encouragement, support and an understanding environment.

One of the biggest challenges is that the disease is hard to trace because the symptoms mask themselves as very common issues like rheumatoid arthritis, fibromyalgia, neuropathy, and a host of other things (Horowitz, 2013). According to Horowitz (2013), the infections that accompany Lyme are just as dangerous and create just as many issues as the disease. With all these issues, it is critical for people who suffer this disease to share their story, in order to help educate others. In this way, it becomes community education. Formal and informal support groups provide a forum for understanding, education, hope, and compassion. They serve as

community-based education organizations and can raise the awareness for those who have the illness, those who care for the ill, and others who want to advocate for prevention. Lyme is the HIV/AIDS of our time and more awareness, prevention, and treatment options need to be in the forefront of the medical field and insurance industries.

Through this study, the participants shared information about medicines, herbal treatments, programs that help ease joint pain, how to prepare food, and a host of other topics. Additionally, information about exercise programs, massage therapy treatments, conversations with medical professionals, insurance representatives, and nutrition classes were all discussed. These activities also continue within the Lyme support group.

According to Bush and Donaldson-Feilder (2009), sharing one's story allows for safe disclosure of issues and provides participants with support, which is much needed in this area. Bush and Donaldson-Feilder (2009) go on to say that the opportunities for conversations allows reflection on self and process, learning from others, and learning about self. All components are essential when working through the life changes that occur once diagnosed with Lyme.

As Butow et al. (2006) wrote, engaging participants allows for an opportunity to understand concerns, provide interactions, and allow for self to reveal feelings and beliefs, and offers support, hope, protection, and comfort. These practices provide good communication and set a foundation to build relationships. Brown and Tregea (2013) shared that participants have to feel that they belong and that close friendships are being cultivated. Knox, Huff, Graham, Henry, Branch, Henderson, and Emsermann (2015) acknowledged that sharing, through informal learning, helps individuals manage their chronic conditions by connecting them with peers from similar life circumstances or with similar health conditions.

Hansman (2016) described how understanding learners, organizations, learning contexts, and outcomes lead to relationships that help with self-esteem, friendships and mentoring possibilities. Varpio, Bidlake, Casimiro, Hall, Kuziemy, Brajtman, and Humphrey-Murto (2014) stated that informal learning has long been recognized as an important contribution to health professions and education. As we have discovered, this process of informal learning, according to Yanchar and Hawkley (2014), allows for meaningful experiences where participants become more familiar, perceptive, and capable within their cultural forms of life. By sharing information, being critically reflective, and cultivating friendships the environment of a supportive group, meaning I am not facing this disease alone, becomes safe and there is an ease about discussion the details of the disease and how to cope with it.

Ziegler, Paulus, and Woodside (2014) added that the learning taking place between people, rather than within the individual mind, provides necessary support. With everything set in place and all components working together, there are still changes and evolution that takes place. Ziegler et al. (2014) shared that community members make meaning together as they note their experiences, reinterpret their experiences together, theorize by creating abstracts and explanations, and question assumptions. Through these practices the community soon realizes where growth and changes need to be made. Ultimately, as stated by Ziegler et al. (2014), informal learning through shared experiences and interest are what keeps communities together and is considered legitimate informal learning that teaches us not only how to do, but how to be a member of a support community.

As I reflect on the community support group, what it stands for, and what it means to those that attend, there is a strong feeling of support, care, and determination. Support for each other through good and bad news. Care for each other with the sharing of knowledge, and it



provides a platform for discussing treatments, medical practices and options, and what to expect. When a group member states that their medical professional told them they would never be cured and that the goal was just to increase their immune system to try to provide them a normal life, the support of the group talks through what that might look or feel like. They share ideas of diet, exercise, and other things they have tried. Diener (2017) stated that raising awareness and educating each other is critical to self-awareness and stability.

### **My Thoughts**

As I reflect on the process taken to write this piece and I review my notes from each interview, I can clearly see that each interview affected me differently. I walked away from some with a feeling of hope that I had help getting the story of Lyme into the world to educate and save people from suffering with this disease. I walked away from others in tears, depressed, full of pain, and in need of my own prayer time. I also walked away from them all with a sense of deep frustration that we are being excluded from medical assistance. We have little to no insurance assistance, no vaccine, and are not being heard within the Center for Disease Control to even identify Lyme disease as a chronic illness.

The realization that there are people just like me who are suffering, in need of knowledge, and who are trying to live hopeful lives provides a deep sense of needed advocacy and hope. Hope that one day there will be a cure. One day there will be enough research to stop the controversy and start the healing process. Hope that one day Lyme will not be a disease that medical providers have very little knowledge about, or those that do are no longer being sued over.

As I sit here writing this last piece I can feel the weight and criticalness of this disease. I hear stories every day of someone being diagnosed and my heart hurts for them. I watch young

parents placing their children on the grass and I just want to ask if they are aware of what happens if their child is bitten. I see people taking hikes, going deer hunting, and just enjoying a night time fire and I just want to tell them to be cautious and wear Deet. I won't say that I have become paranoid, but very vigilant and outspoken would better describe my plight in life.

I also found that community education is needed through many different styles. Informal learning through physical support groups, informative brochures created and shared, social medical groups open – not by invitation only – so that the world can see into our lives, and the creation of conversations within the government and other areas of policy making are a few areas to start.

Throughout the process of the creation of this study there were many times when I wondered if this study was important or if I could make sense of and share the critical aspects of Lyme. I believe that what I have provided is a good first step to get the conversation started. The topic of Lyme disease is vast and there are so many areas that still need research conducted. I believe those areas are where my recommendations for future studies come into play.

### **Recommendations for Patients and Family Members**

Dr. Jemsek stated we have to train people, somebody in the family has to learn to take care of the person with this illness (personal communication May 15, 2018). Training needs to be setup in two different manners. The first is training through community education classes. These classes would provide information on how to prevent tick bites, how to spot an infected area, how to remove a tick, and where to find facts about Lyme disease. Another area that would benefit from a community education class is how to prepare appropriate food for a clean and free diet. How to blanch vegetables and dry fruits would be a great place to start.

The second recommendation is the creation of more support groups. Currently, there are two support groups within Indiana, central and southern. People with Lyme disease go to these groups to obtain hope from one another. Lyme patients do not usually feel like traveling far, so groups need to be setup within an hour of major cities. Additionally, the creation of support groups for family members that are caregiving need to be created. Family members need to be educated on the disease and how best to assist their family member. Topics like how to care for a PICC line, what to expect when hurting occurs, and how to setup multiple pill cases all while journaling progress and issues.

Studies need to be conducted to determine what type of family support is needed for Lyme disease patients so that appropriate care can be provided by family members. As well as how to keep families together through the difficult times and how to make life changes to be inclusive of the “new norm” of life that Lyme patients experience.

A note to family members of Lyme sufferers, please know that while you hurting and trying to figure out what is going on with your family member, the Lyme sufferer is going through the same process. Most Lyme sufferers are afraid to let people know how they are feeling, especially when their medical provider has already told them, multiple times, it is all in their head. Be supportive and open to what they are saying. The more you can talk and work through the disease together the better the outcome will be for all concerned.

### **Recommendations for Medical Providers**

Dr. Jemsek stated it best by saying “learn from your patients” (personal communication, May 15, 2018). Lyme disease is so complex that there is no way to know or understand it all. There needs to be a call to action to create a college or a series of courses to help educate medical providers. Dr. Jemsek called this a center of intellectual excellence (personal

communication, May 15, 2018) and the curriculum, leading to a Master's degree, needs to certify doctors to diagnose and treat Lyme disease.

McFadzean (2012) outlined eight key actions that medical providers should do to better understand Lyme disease within their patients.

- Complete physician training programs through the International Lyme and Association Disease Society (ILADS) and hold annual conferences around Lyme disease.
- When patients have multiple system illnesses, consider Lyme.
- Do not rule out Lyme even if the patient does not remember a tick bite or a rash.
- Lab work needs to be done to diagnosis co-infections.
- IGenex, ELISA, Western Blot to determine if Borrelia exists.
- Treatment protocols are complex and most are long in duration, high doses of strong medications, and a combination of multiple medications should be used.
- Be willing to medicate within a team approach. Combine medical professionals, massage therapists, counselors, and healthcare providers
- Do not tell Lyme patients the disease is all in their heads.

These actions start the process of learning about the patient and the disease separately and collectively.

A study needs to be crafted regarding what type of Lyme training is provided during medical school, what type of continuing education courses are being offered to seasoned medical providers, and what type of collaborative training of Lyme can be created.

### **Recommendations for Policy Makers**

The Center for Disease Control sets the standards for insurance companies. This means that when the Center for Disease Control states there is no chronic Lyme disease or when they

place strict criterion on diagnoses, less money is paid out for patients' medical care. Policy makers need to re-exam symptoms and diagnosis. Policy makers need to establish a protocol and payment option for holistic herbal treatments. Dr. Jemsek stated that there were 202 patents regarding Lyme disease (personal communication, May 15, 2018). While the Center for Disease Control does not write the guidelines those that sit on the board hold patents that could provide cures or processes that could slow the epidemic. Policy makers need to keep patients in the forefront of every policy they create.

McFadzean (2012) shared that the Center for Disease Control was asked to correct the misuse of the surveillance criteria, but this has not been done. Public Law (2002) 107-116, which was signed by President George Bush on January 10, 2002, encouraged the Center for Disease Control to work closely with the FDA to ensure that all reports of Lyme disease are expeditiously investigated to ensure public safety so the LymeRix vaccine can be distributed. Investigators should pay close attention. This step must be taken by policy makers so that those with Lyme disease receive appropriate and helpful medical treatments.

Studies recommended for policy makers would include how to obtain medical coverage for Lyme patients and why they are not being acknowledged with treatment options or vaccines.

### **Recommendations for Researchers**

McFadzean (2012) stated, Lyme patients need love an understanding and a kind, non-judgmental, listening ear. They have had too many experiences of being cut off, dismissed, judged, ridiculed, and shut down by family members, friends, medical professionals, and health care providers.

The topic of Lyme disease is large and this study could have taken many turns, but learning about the community of those with Lyme and hearing about their experiences was, to

my way of thinking, critical. There are many recommendations for additional studies that could be proposed, as we just read. Medical professionals need to have more education within the study of Lyme. Research needs to be conducted into what is presented in medical school, what type of continuing education courses are designed with Lyme in mind, and what community education programs are available to assist.

The Center for Disease Control has a responsibility to assist medical professionals by providing medications that would assist Lyme patients to healing. The Center for Disease Control has to protect the medical field and provide the medical providers with training. Other research areas might include why medical insurance is not accepted and how to get this changed. What drives the CDC, medical insurance agencies, and 'big pharm' to determine which chronic illnesses are able to be covered and which cannot, an important area of research that needs to be addressed for changes to be made.

Lyme disease is such a large topic that additional studies need to be done on effective support, effective treatments, effective diets, and what or how does healing look like, or is healing even an option. Diener (2017) shared

I believe that the refusal to deal with Lyme disease will become in time a medical tragedy and embarrassment to our medical healthcare system. Many sources speak of Lyme as being in epidemic proportions, yet hundreds of thousands of people suffer unimaginably. Medical insurance and doctors deny care based on a scandal coming from powers at the top. Physicians such as Dr. Jemsek who follow their Hippocratic Oath of 'do no harm' and treat patients with care and dignity, are truly some of the most courageous heroes out there. (p. 147).

There is hope among those with Lyme. Hope that healing can happen, hope for assistance however that looks, and hope that the suffering that is experienced will produce wisdom for self and others.

### **Researcher Reflections**

Leaving the first, and then many other, Lyme meeting(s) I found a sense of peace, something that has been missing for quite a while. I was relieved that I did not have to explain or defend myself for the way I was feeling, acting, or behaving. The relief was audible in breath and visible in body language.

I reflected on the process of meeting the support group, creating relationships with the participants, and the process that was taken for interviews. It occurred to me that I had to first accept my illness and had to be willing to reach out to others for support. This was a struggle for me, but one of the best things I have done for myself through this journey.

Through these conversations there were many tears and a lot of understanding. There was laughter, as well as empathy and compassion shared and experienced. The walls of isolation were torn down allowing friendships to emerge. When it was time to put the stories together, I struggled. Not with the process, but I struggled with the most effective way to get the attention of readers so that they could feel the pain, sense the urgency and need for assist, and to show that hope is a critical component to healing.

Charon (2006) stated that while narrative competence might alter what a doctor does in the office, the narrative fundamentally shifts what is done with oneself. This is important to understand and the reason why the findings were created in the order and form presented. The fundamental knowledge that being outside could create a situation of life threatening illness was the most logical starting point. The journey and stories then lead the reader through a maze of

symptoms, emotions, uncertainties, and small victories in an effort to create an understanding of the life lived with Lyme disease. The final poem was then created to show that no matter the pain, suffering, and losses that as those with critical illnesses become a new form of self, there is a freedom from the bondage of illness.

### **Research Conclusion and Implications**

The study of Lyme disease has many facets and is difficult to study. I chose to focus on the stories of those living with Lyme as there is not a lot of research devoted to having their voices heard. The intent of this study was to provide a platform for relationships to be formed and for stories to be heard. Going forward much more work needs to be done to unpack all the symptoms and treatments associated with Lyme disease. The reason this study is so important is because Lyme disease could happen to you. Diener (2017) stated that the fact that chronic Lyme has affected hundreds of thousands of people in the United States is proof that creating an awareness is critical. Living with an invisible disease where people continuously do not believe you are suffering warrants a platform.

The conversations and stories from those with Lyme disease add to the literature by providing real life examples to provide hope, encouragement, and suggestions to obtain assistance. As I started this I knew that there were Lyme patients that were struggling. I did not know to the extent, outside of my own journey, or how similar all of our stories really are. This realization is what made this study so important. Dr. Len stated, (personal communication, June 1, 2018), if more than one person is experiencing the same thing, there is a truth there. If there is a truth of what Lyme patients are experiencing then why are they being ignored, excluded, and made to feel as if their experiences are not important within the medical field? There are several studies that can and should be created from this very question.



## Chapter Summary

The chapter recounted the findings, provided recommendations for future studies, and provided reflections from the research study. There are still many unanswered questions, but the conversation has started. Diener (2017) described that the people with Lyme live with an invisible disease. They look well on the outside, but inside they feel like they are dying. Ultimately what makes the difference to Lyme patients is supportive and knowledgeable people with whom to share the journey. Diener (2017) concludes with a quote from Kenneth B. Liegner, MD,

In the fullness of time, the mainstream handling of chronic Lyme disease will be viewed as one of the most shameful episodes in the history of medicine because elements of academic medicine, elements of government, and virtually the entire insurance industry have colluded to deny a disease. This has resulted in the needless suffering of many individuals who deteriorate and sometimes die for lack of timely applications of treatment or denial of treatment beyond some arbitrary duration. (p. 146).

As I reflect on this journey I am reminded that my story is very similar to those of my participants. I get discouraged, I wonder why me, I long to be healthy, and I wonder if I will ever be able to be active like I used to be. The good days provide hope and the bad days force me to open the Bible to find answers. Psalm 73:29 reminds me that “my health may fail and my spirit grow weak, but God is the strength of my heart.” Also, Hebrews 11:1 provides “faith in the confidence that what we hope for will actually happen; it gives us assurance about things we do not see.” I have a choice, I can let

Lyme disease guide my life, or I can live my life to the fullest with Lyme. I choose to live! This is the story of Lyme.

## REFERENCES

- Adegbola, M. (2006). Spirituality and quality of life in chronic illness. *The Journal of Theory Construction & Testing*, 10(2), 42-46.
- Adams, T. B., Bezner, J. R., Drabbs, M. E., Zambarano, R. J., & Steinhardt, M. A. (2000). Conceptualization and measurement of the spiritual and psychological dimensions of wellness in a college population. *Journal of American College Health*, 48(4), 165.
- Ali, A., Vitulano, L., Lee, R., Weiss, T. R., & Colson, E. R. (2014). Experiences of patients identifying with chronic Lyme disease in the healthcare system: *A qualitative study*. *BioMed Central*, 15(79).
- Armstrong, P. M., Brunet, L. R., Spielman, A., & Telford III, S. R. (2001). Risk of Lyme disease: Perceptions of residents of a long star tick-infested community. *Bulletin of The World Health Organization*, 79(10), 916.
- Aucott, J., Rebman, A., Crowder, L. & Krotte, K. (2012). Post-treatment Lyme disease syndrome symptomatology and the impact on life functioning: Is there something here? Quality of Life Research. *An International Journal of Quality of Life Aspect of Treatment, Care and Rehabilitation*, 22(1), 75-84.
- Baalen, S., & Boon, M. (2015). An epistemological shift: From evidence-based medicine to epistemological responsibility. *Journal of Evaluation in Clinical Practice*, 21(3), 433-439.
- Barinaga, M. (1992). Furor at Lyme disease conference. *Science*, 256(5062), 1384-1385.
- Bogdan, R. C., & Biklen, S. K. (2007). *Qualitative research for education: An introduction to theories and methods*. New York, NY: Pearson.

- Brglez, M. (2001). Reconsidering wendt's meta-theory: Blending scientific realism with social constructivism. *Journal of International Relations & Development*, 4(4), 339.
- Broken. (2015). *Learn about Lyme*. Retrieved from [www.brokenquiet.wordpress.com](http://www.brokenquiet.wordpress.com).
- Brown, K., & Tregea, S. (2013). What makes a successful peer-led aphasia support group? *Aphasiology*, 27(5), 581-598.
- Buhner, S. H. (2013). *Healing Lyme disease coinfections: Complementary and holistic treatments for bartonella and mycoplasma*. Rochester, VT: Healing Arts Press.
- Bush, K., & Donaldson-Feilder, E. (2009). Achieving effective supervision for coaching psychologists: Exploring a peer supervision/reflective learning group model. *The Coaching Psychologist*, 5(1), 34-38.
- Butow, P., Kristen, L., & Price, M. (2006). Support and training needs of cancer support group leaders: A review. *Psycho-Oncology*, 15(8), 651-663.
- Caffarella, R. S., & Daffron, S.R. (2013). *Planning programs for adult learners: A practical guide*. San Francisco, CA: Jossey-Bass.
- Carr, D. (1986). *Time, narrative, and history*. Bloomington, IN: Indiana University Press.
- CDC. (2015, September 30). *How many people get Lyme disease*. Retrieved from <http://www.cdc.gov/lyme/stats/humancases.html>.
- Chaaya, G., Jaller-Char, J. J., & Ali, S. K. (2016). Beyond the bull's eye: Recognizing Lyme disease. *Journal of Family Practice*. 65(6), 373-379.
- Chapin, M. H., & Byrne, A. M. (2013). Ethical decision making applied to social networking. *Journal of Rehabilitation*, 79(3), 11-16.
- Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. New York, New York: Oxford University Press

- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in Qualitative research*. San Francisco, CA: Jossey-Bass.
- Clandinin, D. J., & Connelly, F. M. (2006). Narrative inquiry. In Green, J., Camilli, G. and Elmore, P. (Eds). *Handbook of complementary methods in education research*. 375-385. Mahwah NJ: Lawrence Erlbaum.
- Clandinin, D. J., & Murphy, S. (2007). Looking ahead: Conversations with Elliott Mishler, Don Polkinghorne, and Amia Lieblich. In Clandinin, D. J. (Ed). *Handbook of narrative inquiry: Mapping a methodology*. 632-650. Thousand Oaks, CA: Sage.
- Clandinin, D. J., & Rosiek, J. (2007). Mapping a landscape of narrative inquiry: Borderland spaces and tensions. In Clandinin, D. J. (Ed.), *Handbook of narrative inquiry: Mapping a methodology*. 35-75. Thousand Oaks, CA: Sage.
- Clark, C. R. (1993). Social responsibility ethics: Doing right, doing good, doing well *Ethics & Behavior*, 3(3-4), 303-327.
- Cocks, P. M. (2014, November). Freedom of information act spoils secrecy. *The Lyme Times*, 26(2), 23-24.
- Cohen, S. (2004). Social relationships and health. *American Psychologist*, 59(8). 676-684.
- Connelly, F. M. & Clandinin, D. J. (1990). Stories of experience and narrative inquiry. *Educational Researcher*, 19(5), 2-14.
- Craig, C. & Huber, J. (2007). Relational reverberations: Shaping and reshaping narrative inquiries in the midst of storied lives and contexts. In Clandinin, D. J. (Ed.). *Handbook of narrative inquiry: Mapping a methodology*. 251-279. Thousand Oaks, CA: Sage.

- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Creswell, J. W. (2013). *Qualitative inquiry & research design: Choosing among five approaches*. Thousand Oaks, CA: Sage.
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Thousand Oaks, CA: Sage.
- Deggs, D., & Miller, M. (2011). Developing community expectations: The critical role of adult educators. *Adult Learning*, 22(3), 25-30.
- Denzin, N. K., & Lincoln, Y. S. (1994). *The SAGE handbook of qualitative research*. Thousand Oaks, CA: Sage.
- Denzin, N. K., & Lincoln, Y. S. (2008). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The landscape of qualitative research* (3<sup>rd</sup> ed., pp. 1-44). Thousand Oaks, CA: Sage.
- Denzin, N. K., & Lincoln, Y. S. (2011). *The sage handbook of qualitative research*. Thousand Oaks, CA: Sage.
- Diener, T. (2017). *My journey towards healing battling Lyme disease*. Sugarcreek, OH: Carlisle.
- Faith. (2017). *Rebecca Wells*. Retrieved from Quotefancy.com.
- Fallon, B. A. (2004). Neuropsychiatric Lyme disease: The new 'great imitator'. *Psychiatric Times*, 21(6), 44-48.

- Fallon, B. A., Pavlicova, M., Coffino, W. W., & Brenner, C. (2014). A comparison of Lyme disease serologic test results from 4 laboratories in patients with persistent symptoms after antibiotic treatment. *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America*, 59(12), 1705-1710.
- Faulkner, S. L. (2009). *Poetry as method: Reporting research through verse*. New York, NY: Left Coast Press.
- Fetterman, D. M. (1998). *Ethnography: Step by step*. Applied Social Research Methods Series, 17. Thousand Oaks, CA: Sage.
- Gehart, D. (2007). *Mastering competencies in family therapy: A practical approach to theory and clinical case documentation*. Boston, MA: Cengage.
- Gifford, B. (2016, September). Tick, tick, tick. *Men's Health*, 31(7), 83-87.
- Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3(1). 42-55.
- Guba, E. G., & Lincoln, Y. S. (1982). Epistemological and methodological bases of naturalistic inquiry educational communications and technology. In Y. Lincoln. *Qualitative Inquiry: Vol 30*. (pp. 233-252).
- Hader, R. (2005, April). Carve out time to think-yes, think. *Nursing Management*, 36(4), 4.
- Hampshire, K., Iqbal, N., Blell, M. & Simpson, B. (2014). The interview as narrative ethnography: Seeking and shaping connections in qualitative research. *International Journal of Social Research Methodology*, 17(3), 215-231.

- Hansman, C.A. (2016). Mentoring and informal learning as continuing professional education. In M. Coady (Ed.), *New Directions for Adult & Continuing Education: Vol 151. Contexts, Practices and Challenges: Critical Insights from Continuing Professional Education*. (pp. 31-41). Hoboken, NJ: Wiley.
- Harrop, D., & Turpin, B. (2013). A study exploring learners' informal learning space, behaviors, attitudes, and preferences. *New Review of Academic Librarianship*, 19(1), 58-77.
- Hart-Smith, V. (1987). Creating and managing a peer group. *Nursing*, 17(2), 8aa-8bb.
- Hatch, J. A. (2002). *Doing qualitative research in education settings*. Albany, NY: State University of New York Press.
- Hatcher, T., & Storberg-Walker, J. (2003). Developing ethical adult educators: A re-examination of the need for a code of ethics. *Adult Learning*, 14(2), 21-24.
- Heaton, J., Raisanen, U., Salinas, M. (2016). Rule your condition, don't let it rule you: Young adults' sense of mastery in their accounts of growing up with a chronic illness. *Sociology of Health & Illness*, 38(1), 3-20.
- Henton, D., Melville, J., & Walesh, K. (2014). *Civic revolutionaries*. San Francisco, CA: Jossey-Bass.
- Hertz, R. (1997). *Reflexivity and voice*. London: SAGE.
- Hettler, B. (1976). *Six dimensions of wellness model*. National Wellness Institute. Retrieved from <http://www.NationalWellness.org>.
- Horowitz, R. I. (2013). *Why can't I get better? Solving the mystery of Lyme and chronic disease*. New York, NY: St. Martin's Press.



- Horowitz, R. I. (2017). *How can I get better? An action plan for treating resistant Lyme & chronic disease*. New York, NY: St. Martin's Press.
- Hovland, K. (2009). Global learning: What is it? Who is responsible for it? *Peer Review*, 11(4), 4-7.
- Hu, L. T. (2016). Lyme disease. *Annals of Internal Medicine*, 164(9), ITC65-ITC79.
- Huang, G. H. C. (2006). Informal forum: Fostering active learning in a teacher preparation program. *Education*, 127(1), 31-39.
- Josselson, R. (1996). *Ethics and process in the narrative study of lives*. London: Sage.
- Kakkad, D. (2005). A new ethical praxis: Psychologists' emerging responsibilities in issues of social justice. *Ethics & Behavior*, 15(4), 293-308.
- Kelleher, D. (1988). Coming to terms with diabetes: Coping strategies and non-compliance. In Anderson, R. and Bury, M. (Eds.). *Living with Chronic Illness: The Experiences of Patients and their Families*. London: Unwin Hyman.
- Knox, L., Huff, J., Graham, D., Henry, M., Bracho, A., Henderson, C., & Emsermann, C. (2015). What peer mentoring adds to already good patient care: Implementing the carpenteria peer mentoring program in a well-resourced health care system. *The Annals of Family Medicine*, 13(1), S59-S65.
- Lantos, P. M., Shapiro, E. D., Auwaerter, P. G., Baker, P. J., Halperin, J. J., McSweeney, E., & Wormser, G. P. (2015). Unorthodox alternative therapies marketed to treat Lyme disease. *Clinical Infectious Diseases*, 60(12), 1776-1782.
- Larkin, M. & Thompson, A. (2012). Interpretative phenomenological analysis. *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*, 101-116.

- LDA. (n.d.) *Lyme in countries worldwide*. Retrieved from <https://www.lymediseaseassociation.org/index.php/about-lyme/cases-stats-maps-a-graphs/940-lyme-in-more-than-80-countries-worldwide>.
- Leavy, P. (2014). *The oxford handbook of qualitative research*. New York, NY: Oxford University Press.
- Lee, A. A., Piette, J. D., Heisler, M., Janevic, M. R., Langa, K. M., & Rosland, A. (2017). Family members' experiences supporting adults with chronic illness: A national survey. *Families, Systems & Health: The Journal of Collaborative Family Healthcare*, 35(4), 463-473.
- Levy, S. (2013). The Lyme disease debate. *Environmental Health Perspectives*, 121(4), A120-A125.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage.
- Ljostad, U., & Mygland, A. (2012). The phenomenon of chronic Lyme: An observational study. *European Journal of Neurology*, 19, 1128-1135.
- Lough, B. J., & Thomas, M. M. (2014). Building a community of young leaders: Experiential learning in Jewish social justice. *Journal of Experiential Education*, 37(3), 248-264.
- Mahr, G. (2015). Narrative medicine and decision-making capacity. *Journal of Evaluation in Clinical Practice*, 21, 503-507. doi:10.1111/jp.12357.
- Maraspin, V., Ruzic-Sabljić, R., Lusa, L., & Strle, F. (2015). Course and outcome of early Lyme borreliosis in patients with hematological malignancies. *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America*, 61(3), 427-431.

- Maxwell, J. A. (2005). *Qualitative research design: An interactive approach* (2<sup>nd</sup> ed., Applied Social Research Methods Series, Vol. 42). Thousand Oaks, CA: Sage.
- McFadzean, N. (2010). *The Lyme diet: Nutritional strategies for healing from Lyme Disease*. South Lake Tahoe, CA: BioMed Publishing Group.
- McFadzean, N. (2012). *The beginner's guide to Lyme disease: Diagnosis and treatment made simple*. South Lake Tahoe, CA: BioMed Publishing Group.
- McSherry W., & Draper, P. (1998). The debates emerging from the literature surrounding the concept of spirituality as supplied to nursing. *Journal of Advanced Nursing*, 27(4), 683.
- Medicinenet. (n. d.). *MedTerms medical dictionary*. Retrieved from [www.medicinenet.com](http://www.medicinenet.com).
- Merriam, S. B. (2002). Introduction to qualitative research. In S. B. Merriam & Associates (Eds.). *Qualitative research in practice: Examples for discussion and analysis* (pp. 3-17). San Francisco, CA: Jossey-Bass.
- Merriam, S. B. (2014). *Global issues and adult education: Perspective from Latin America*. Hoboken, NJ: John Wiley & Sons.
- Merriam, S. B., & Brockett, R. G. (2007). *The profession and practice of adult education*. San Francisco, CA: Jossey-Bass.
- Merriam, S. B., & Simpson, E. L. (1984). *A guide to research for educators and trainers of adults*. Malabar, FL: Krieger Publishing.
- Merriam, S. B., & Simpson, E. L. (2000). *A guide to research for educators and trainers for adults* (2<sup>nd</sup> ed.). Malabar, FL: Krieger Publishing Company.
- Merriam-Webster. (May 12, 2018). *Dictionary*. Retrieved from [merriam-webster.com](http://merriam-webster.com).
- Mervine, P. (2014, May). The pioneers. *The Lyme Times*, 26(1), 15-23.

- Molee, L. M., Henry, M. E., Sessa, V. I., & McKinney-Prupis, E. R. (2011). Assessing learning in service-learning courses through critical reflection. *Journal of Experiential Education*, 33(3), 239-257.
- Moser, M. M. (2011). Treatment for a 14-year-old girl with Lyme disease using therapeutic exercise and gait training. *Physical Therapy*, 91(9), 1412-1423.
- Moyer, J. M., & Sinclair, A. J. (2016). Stoking the dialogue on the domains of transformative learning theory. *Adult Education Quarterly*, 66(1), 39-56.
- Nadelman, R. B., & Wormser, G. P., (2007). Reinfection in patients with Lyme disease. *Clinical Infectious Diseases*, 45, 1032-1038.
- Nationalwellness. (n. d.). *Definition of wellness*. Retrieved from nationalwellness.org
- Nelson, H. I. (2008). *Damages identities, narrative repair*. Ithaca, NY: Cornell University Press.
- Nhat Hanh, T. (2017). *How to fight*. Berkley, CA: Parallax.
- Noddings, N. (1986). Fidelity in teaching, teacher education, and research for teaching. *Harvard Educational Review*, 56(4), 496-510.
- Nolan, K., & Mauer, M. P. (2006). An evaluation of a Lyme disease prevention program in a working population. *American Journal of Health Promotion*, 20(6), 379-382.
- O'Sullivan, E. V., Morrell, A., & O'Connor, M.A. (2002). *Expanding the boundaries of transformative learning*. New York, NY: Palgrave.
- Paparone, P. (2016). The summer scourge of Lyme disease. *The American Journal of Nursing*, 90(6), 44-47.

- Patrick, D. M., Miller, R. R., Gardy, J. L., Parker, S. M., Morshed, M. G., Steiner, T. S., Singer, J., Shojania, K., & Tang, P. (2015). Lyme disease diagnosed by alternative methods: A phenotype similar to that of chronic fatigue syndrome. *Clinical Infectious Diseases*, 61(7), 1084-1091.
- Pauldine, E. F. (2003). Taking a bit out of Lyme disease. *Nursing*, 33(4), 49-52.
- Piacentino, J. D., & Schwartz, B. S. (2002). Occupational risk of Lyme disease: An epidemiological review. *Occupational and Environmental Medicine*, 59(2), 75-84.
- Polkinghorne, D. E. (1995). Narrative configuration in Qualitative analysis. *International Journal of Qualitative Studies in Education*, 8(1), 5-23.
- Public Law. (2002). 107<sup>th</sup> congress public law 107-116. Retrieved from Congress.Gov.
- Roberts, D. (2008). Learning in clinical practice: The importance of peers. *Nursing Standard*, 23(12), 35-41.
- Rowe, M. M. & Allen, R. G. (2004). Spirituality as a means of coping with chronic illness. *American Journal of Health Studies*, 19(1), 62-67.
- Rowe, P. M. (2000). Chronic Lyme disease: The debate goes on. *Lancet*, 355(9213), 1436.
- Russ-Eft, D., & Preskill, H. (2009). *Evaluation in organizations: A systematic approach to enhancing learning, performance, and change*. New York, NY: Basic Books.
- Sarris, G. (1993). *Keeping slug woman alive: A holistic approach to American Indian tests*: Los Angeles, CA: University of California Press.
- Savin-Baden, M., & Howell Major, C. (2013). *Qualitative research: The essential guide to theory and practice*. New York, NY: Routledge.

- Schwartz, A. J. (2015). Inspiring and equipping students to be ethical leaders. In A. Schwartz. *New Directions for Student Leadership: Vol 146. Developing Ethical Leaders* (pp. 5-16). New York, NY: Wiley.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretive phenomenological analysis: Theory, method and research. In L. Tindall. *Qualitative research in psychology: Vol 4.* (pp. 346-347).
- Snelgrove, R., Wood, L., & Carr, K. (2016). Emerging adults with chronic illness pursuing and enhancing leisure. *Leisure Sciences*, 38(1), 34-49.
- Solomon, M., Pistrang, N., & Barker, C. (2001). The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology*, 29(1), 113.
- Sophantastic. (2017). *Lyme is a torture box*. Retrieved from [www.sophantastic.org](http://www.sophantastic.org).
- Terrible Tiny Tales. (2017). *Writing is a chronic disease*. Retrieved from [facebook.com](https://www.facebook.com/terribletinytales).
- Unesdoc. United Nations Educational Scientific and Cultural Organization. (2005). *Guidelines for inclusion: Ensuring accessing to education for all*. Retrieved from [www.unesdoc.unesco.org](http://www.unesdoc.unesco.org).
- Vagle, M. D. (2014). *Crafting phenomenological research*. Walnut Creek, CA: Left Coast Press.
- Varpio, L., Bidlake, E., Casimiro, L., Hall, P., Kuziemy, C., Brajtman, S., & Humphrey Murto, S. (2014). Resident experiences of informal education: How often, from whom, about what and how. *Medical Education*, 48(12), 1220-1234.
- Waghid, Y. (2007). Education, responsibility and democratic justice: Cultivating friendship to alleviate some of the injustices on the African continent. *Education Philosophy and Theory*, 39(2), 182-196.

- Warren, D. (1996). Because you loved me (Recorded by Celine Dion). *On Falling into You* (CD). Los Angeles, CA: Columbia-Epic.
- Watson, J. (1985). *Nursing: Human science and human care: A through of nursing*. Norfolk, CT: Appleton-Century Crofts.
- WebMD Medical Reference from Healthwise. (2014, June). *Stages of Lyme disease*. WebMD. Retrieved from <http://www.webmd.com/arthritis/tc/stages-of-lyme-disease>.
- Wickens, A. (2005). Healing Lyme natural prevention and treatment of Lyme borreliosis and its coinfections. *Library Journal*, 130(17), 75.
- Wright, P., & Mervin, P. (2000). Diagnosing Lyme disease. *British Medical Journal*, 320(7227), 121. Retrieved from <http://www.jstor.org/stable/25186808>.
- Yanchar, S., & Hawkley, M. (2014). There's got to be a better way to do this: A qualitative investigation of informal learning among instructional designers. *Educational Technology Research & Development*, 62(3), 271-291.
- Yardley, W. (2014, November). Willy Burgdorfer, who found bacteria that cause Lyme disease, is dead at 89. *The New York Times*. Retrieved from <https://www.nytimes.com/2014/11/20/health>.
- Yuan, Y. C., Gay, G., & Hembrooke, H. (2006). Focused activities and the development of social capital in a distributed learning community. *The Information Society*, 22(1), 25-39.
- Ziegler, M. F., Paulus, T., & Woodside, M. (2014). Understanding informal group learning in online communities through discourse analysis. *Adult Education Quarterly*, 64(1), 60-78.

**APPENDIX A**  
**IRB APPROVAL**

Date: 3/28/2018 10:48 AM

To: "Amy Ward" <amward2@bsu.edu>, "Michelle Glowacki-Dudka" <mdudka@bsu.edu>

From: "John Mulcahy" <no-reply@irbnet.org>

Reply To: "John Mulcahy" <jmulcahy@bsu.edu>

Subject: IRBNet Board Document Published

Please note that Ball State University IRB has published the following Board Document on IRBNet:

Project Title: [1011591-1] A Poetic Narrative Inquiry Into the Lives of People With Lyme Disease

Principal Investigator: Amy Ward, MA

Submission Type: New Project

Date Submitted: January 22, 2017

Document Type: Exempt Letter

Document Description: Exempt Letter

Publish Date: January 25, 2017

Should you have any questions you may contact John Mulcahy at [jmulcahy@bsu.edu](mailto:jmulcahy@bsu.edu).

Thank you,

The IRBNet Support Team

[www.irbnet.org](http://www.irbnet.org)



**APPENDIX B**  
**INFORMED CONSENT – DISSERTATION**

**Survey Informed Consent Form**

**Study Title** A Poetic Narrative Inquiry Into the Lives of People With Lyme Disease

**Study Purpose and Rationale**

The purpose of this narrative inquiry is to understand the struggles and experiences of those with Lyme disease. The group of participants, found through purposeful and snowball sampling techniques, will provide detailed stories through a semi-structured, one-hour interview process. The group of participants will be generally defined as people that have been diagnosed with and have been or are being treated for Lyme as well as those that are providing support for Lyme carriers. Stories will be helpful to fill in gaps in the literature and provide a more cohesive overview of Lyme disease and what people experience.

**Inclusion/Exclusion Criteria**

Must be 18 years of age or older and can be either male or female. You must have been or are being treated for Lyme disease. You must be part of the Lyme network. You must complete a consent form. If you do not meet this criteria, you will not be allowed within this study.

**Participation Procedures and Duration**

You will be asked to meet at a mutually agreed upon location for a one hour semi-structured interview. The interview will be recorded and pseudonyms will be used for all names.

Recording will be transcribed by Rev.Com, a third party transcription company.

**Data Confidentiality**

All data will be maintained confidentially and no identifying information, such as names, will appear in any publication or presentation of the data. Pseudonyms will be used for all names for future publications.

**Storage of Data**

Paper data will be stored in a locked filing cabinet in the researcher's home office for five years and will then be shredded. The data will also be entered into a software program and stored on the researcher's password-protected computer for five years and then deleted. Only the principal investigator and the faculty advisor will have access to the data.

**Risks or Discomforts**

The only anticipated risk from participating in this study is that you may not feel comfortable answering some of the questions. You may choose not to answer any question when feelings are uncomfortable and you may quit the study at any time.

**Benefits**

There is no incentive or compensation being offered for this research study.

**Voluntary Participation**

Your participation in this study is completely voluntary and you are free to withdraw your permission at any time, for any reason, without penalty or prejudice from the investigator.

Please feel free to ask any questions of the investigator before signing this form and at any time during the study.

**IRB Contact Information**

For one's rights as a research subject, you may contact the following: For questions about your rights as a research subject, please contact the Director, Office of Research Integrity, Ball State University, Muncie, IN 47306, (765) 285-5070 or at [irb@bsu.edu](mailto:irb@bsu.edu).

**Researcher Contact Information**

Principal Investigator:  
Amy M. Baize-Ward  
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Email: [mdudka@bsu.edu](mailto:mdudka@bsu.edu)

**Consent**

I, \_\_\_\_\_, agree to participate in this research project entitled, A Poetic Narrative Inquiry Into the Lives of People With Lyme Disease. The study has been explained and all questions have been answered with satisfaction. I have read the description of this project and give my consent to participate. I understand that I will receive a copy of this informed consent form to keep for future reference.

To the best of my knowledge, I meet the inclusion/exclusion criteria for participation (described on the previous page) in this study.

\_\_\_\_\_

Participant's Signature

\_\_\_\_\_

Date

**APPENDIX C**  
**PARTICIPANT RECRUITMENT**

**Email/Phone Script for:**

**A Poetic Narrative Inquiry Into the Lives of People With Lyme Disease**

Hello (name), I am really excited that it is time to start my study what we were discussing a few (days/weeks) ago. I wanted to reach out and see if you are still interested in participating? The focus of this study is to understand more about your journey with Lyme disease.

If yes: Schedule an appointment of time and location that works best for them.

Thank you, I will follow up with an email to remind you of our appointment and location.

If no: Thank you for at least considering the project. If you change your mind, please reach out. Also, if you know of someone that might be interested, would you be so kind as to pass my contact information along?

If no (illness is too much): Thank you for considering the project and I hope you start feeling better. I certainly understand the challenges you are facing, and if your situation changes and you would like to participate, please make contact with me. If not, I certainly understand.

If leaving a voicemail:

Hello (name), this is Amy calling about the Lyme study we discussed a (day/week) ago. When you get a minute, and if you are still interested in sharing your journey with me, would you please call me back by date/time at 765-744-7643.

**APPENDIX D**  
**SEMI-STRUCTURED INTERVIEW QUESTIONS**

A Poetic Narrative Inquiry Into the Lives of People With Lyme Disease

1. What is your story of living with Lyme disease?
2. How would you describe Lyme disease?
3. In as much detail as possible, please tell me about your experiences so far with battling Lyme.
4. How would you categorize yourself at this time?
  - A Chronic
  - b Early stages
  - c How did you come to this knowledge?
5. You mentioned that you experience (symptom), could you elaborate about how that affects your daily functions?
6. What have you read or researched to help with your knowledge of the disease?
7. What are your feelings about the care you are receiving?
8. Do you believe that you will ever be in remission with this disease?
9. Tell me about the daily functions that you have had to relearn.
10. Can you tell me when you first experienced symptoms?
  - a How long did it take to be diagnosed?
  - b How did you feel about learning this information?
11. What does the healing process with Lyme look like to you?

12. How do you handle the physical pain?
13. Could you speak to your emotional and spiritual state? How has it changed?
14. What are issues/symptoms that you have experienced?
15. Could you tell me about when you contracted the disease? How long did it take you to be diagnosed?
16. Would you mind to share with me what your family has experienced?
17. How would you describe your health prior to Lyme?
18. How did you feel when you were diagnosed with Lyme?
19. How has Lyme affected your life?
20. What does having Lyme mean to you?
21. What life changes have you had to make
22. What treatments have you experienced and what have been the side effects or benefits to the treatments from your perspective
23. Where do you draw support and knowledge from (community, family, friends, support groups, internet, newsgroups, etc)
24. What motivates you in your struggles?
25. How do or what can the community, doctors, and patients do to have more effective outcomes
26. Describe your symptoms in detail, if possible.
27. Is there anything that you would like to share with me about your journey with Lyme that you didn't have a chance to already?
28. Would you be open to speaking with me again, if needed?